Dysphagia following acute cervical spinal cord injury (DAISY): identification of current practice and development of a swallow screening tool

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Declaration

I, Jacqueline McRae confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

J. McRae

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Abstract

Cervical spinal cord injury (CSCI) patients have complex needs, often requiring tracheostomy, ventilation and surgery. These multiple factors have been linked to the development of oropharyngeal dysphagia with reported incidences of 8-80%. Resulting complications include respiratory impairment, increased morbidity and prolonged length of stay in an intensive care unit (ICU). This delays transfer to specialised units for on-going rehabilitation. Currently there is no clinical guidance for the effective identification and management of oropharyngeal dysphagia following CSCI. The aim of the DAISY project was to develop a screening tool to improve the recognition of oropharyngeal dysphagia risks. In turn this would lead to earlier intervention and improved outcomes.

The two studies in the first part of the thesis investigated variations in clinical practice between specialised and non-specialised units and across professional groups through the perspective of staff and patients. A multi-disciplinary staff survey revealed significant differences in oropharyngeal dysphagia care, tracheostomy management and ventilatory weaning that were likely to affect outcomes. Interviews with CSCI patients and their carers about their experience of care across multiple settings identified a number of themes reflecting the process of adjustment and transition post-injury. Many reported a long wait for the 'golden opportunity' to transfer to a spinal unit for rehabilitation before recovery could take place. Variable management of eating and communication problems had a long-lasting impact.

In the second part of the thesis, the literature review and study findings generated 85 statements for a Delphi consensus process on oropharyngeal dysphagia risk factors and management. An international expert panel achieved consensus on 73% of statements after two rounds, although methods of screening and assessing oropharyngeal dysphagia remained unclear. Based on these results, the DAISY swallow screening tool was developed and a final study evaluated usability of the tool in two non-specialised units. A pragmatic observational approach was employed to permit the tool to embed in current practice, however staff engagement and participant recruitment was limited making the value of the tool inconclusive tool.

Further multi-site research is needed to evaluate the validity and utility of the DAISY screening tool. Prospective outcome data is required to verify variations in clinical management across units and the contribution of specialist guidance to improve clinical practices.

Table of Contents

List of tables

List of figures

Abbreviations

ACSS Anterior cervical spine surgery
AHP Allied health professional
AIS ASIA impairment scale - a measure of severity of the spinal injury
ASDS Acute Stroke Dysphagia Screen
ASIA American Spinal Injuries Association
BSE Bedside swallow evaluation
CI Chief investigator
CSCI Cervical spinal cord injury
DAISY Dysphagia following acute cervical spinal cord injury
DGH District general hospital
DPRU Delphi Process Research Unit
ENT Ear, nose and throat specialty
FVC Forced vital capacity
FEES Fibre-optic endoscopic evaluation of swallowing
FEV1 Forced Expiratory Volume in 1 second
GPICS Guidelines for the Provision of Intensive Care Services
ICU Intensive care unit
MASA Mann Assessment of Swallow Ability
MTC Major trauma centre
MUST Malnutrition Universal Screening Tool
NICU Neurological intensive care unit
NBM Nil by mouth
NG Nasogastric
PEG Percutaneous endoscopic gastrostomy
PI Principal investigator
PT Physiotherapist
QOL Quality of life
RCSLT Royal College of Speech and Language Therapists
RCT Randomised Controlled Trial
RISCI Respiratory Information for Spinal Cord Injury
SCI Spinal cord injury
SIU Spinal injury unit
SLT Speech and language therapist
SNST Spinal Nutrition Screening Tool
SPH Specialist hospital
SV Speaking valve

TCH Teaching hospital

TOR-BSST Toronto Bedside Swallowing Screening Test

VAP Ventilator associated pneumonia

VC Vital capacity

VFS Videofluoroscopic study of swallowing

WST Water Swallow Test

1. Introduction to the thesis

The function of eating is vital for maintaining life through nutritional intake, with the process of swallowing entailing food passing along the same route as the upper airway. For swallowing to be safe, the musculature and innervation of structures for breathing and eating need to be co-ordinated to prevent inadvertent aspiration of food and fluid into the airway. An impairment of swallowing function is defined as oropharyngeal dysphagia and encompasses problems at the oral stage for chewing, at the pharyngeal stage for bolus transit and at the laryngeal area in terms of aspiration (Groher and Crary, 2015, Logemann, 1998). Oropharyngeal dysphagia has commonly been recognised and reported in those with cortical and brainstem impairments, such as stroke, brain injury and progressive neurological disorders, with negative outcomes (Takizawa et al., 2016). The consequences of oropharyngeal dysphagia include poor nutrition and aspiration pneumonia, which when severe and ongoing, affect morbidity and increase the risk of mortality (Altman et al., 2010). In stroke care, the use of a screening tool aims to achieve early oropharyngeal dysphagia identification, reducing complications and the burden of care through timely interventions (Daniels et al., 2012).

Oropharyngeal dysphagia following spinal cord injury (SCI) is less well understood and therefore poorly recognised due to the absence of cortical or brainstem involvement. The mechanism of impairment differs to other neurological population groups, with causes being multifactorial relating to cord injury, surgery and respiratory interventions (Brady et al., 2004, Abel et al., 2004, Shem et al., 2011). Nevertheless, in recent years, oropharyngeal dysphagia has been acknowledged as a serious complication in cervical spinal cord injury (CSCI) affecting respiratory function and increasing mortality (Chaw et al., 2012, Shem et al., 2012a). This has led to recommendations for early screening and clinical management to reduce complications and length of stay, particularly within an intensive care unit (ICU). Guidance for the management of respiratory weaning (Respiratory Information for Spinal Cord Injury, 2012) and nutrition (Wong et al., 2012b) in SCI patients have been developed in recent years, however, recent searches have failed to detect any protocols or

guidelines for the identification and management of oropharyngeal dysphagia in the SCI population.

Existing methods of screening for oropharyngeal dysphagia are designed to detect coughing or choking after swallowing, however they are not sensitive to silent aspiration, a common feature of oropharyngeal dysphagia in CSCI patients (Shin et al., 2011). Instead instrumental assessments that view the pharynx and larynx during swallowing have been recommended for diagnostic testing (Shem et al., 2012a, Brady et al., 2004). These include either a radiological procedure, called videofluoroscopy (VFS) or a nasendoscopic study named fibre-optic endoscopic evaluation of swallowing (FEES). However, either of these can be challenging to undertake with CSCI patients due to the restrictions of their medical condition making bedside assessments preferable (Shem et al., 2012b). Ideally, a reliable screening test would direct only those patients with positive signs of oropharyngeal dysphagia to further instrumental testing in order to plan specific interventions.

A further challenge for CSCI patients is the site of their care. Their acute clinical management takes place in a major trauma setting, usually a critical care unit, that does not have staff who specialise in SCI management. SCI patients are expected to transfer to a specialised unit, dealing with spinal and neuro-rehabilitation, for on-going care once medically stable (CRG for Spinal Cord Injury, 2016), although delays have been reported due to reduced bed capacity, leaving care to continue in non-specialised units (Spinal Injuries Association, 2015). It is not known how staff in non-specialised units identify or manage oropharyngeal dysphagia in CSCI patients as signs and symptoms may be masked by impairments of the injury itself such as poor respiratory function. This will consequently alter the clinical decisions made for the management of respiratory function, nutrition and oral intake, which may impact clinical outcomes. For people with CSCI, little is known about the consequences of these decisions and whether the variation in settings has an impact on their experiences.

i. Aims and objectives of the thesis

In the absence of SCI-specific guidelines, this project sought to discover previously unidentified information about the care of CSCI patients with oropharyngeal dysphagia, in order to develop clinical tools to improve decision-making and clinical outcomes through two specific aims and four objectives

Aim 1:

To understand the variations in oropharyngeal dysphagia management between specialised and non-specialised units from the perspective of staff and people with CSCI.

Objectives:

- To identify the decisions by MDT staff in specialised and non-specialised units with respect to managing oropharyngeal dysphagia and associated impairments of ventilation, nutrition, oral hygiene and communication.
- To explore the lived experience of people with CSCI and oropharyngeal dysphagia during their admission for acute and rehabilitation care

Aim 2:

To develop a screening tool and guidance for staff to deliver consistent care for CSCI patients with oropharyngeal dysphagia

Objectives:

- To generate expert consensus on the risk factors for oropharyngeal dysphagia in CSCI patients and agreed methods of identification and management
- Undertake a feasibility study of the utility of a swallow screening tool for CSCI patients with suspected oropharyngeal dysphagia for use by staff in non-specialised acute units.

Four studies were undertaken to achieve these aims and objectives. Mixed methodologies were employed to collect the required data (Table 1.1).

Table 1.1 Overview of thesis studies, methodology and data outputs

	Focus of investigation	Methodology	Data outputs
Study 1 (chapter 3)	Current MDT clinical practice with CSCI patients in specialised and non-specialised units	National online web survey	Quantitative and qualitative data
Study 2 (chapter 4)	Lived experience of people with CSCI with oropharyngeal dysphagia in specialised and non-specialised units	Semi-structured interview	Qualitative-thematic analysis
Study 3 (chapter 5)	Expert consensus on oropharyngeal dysphagia risks, methods of identification and management, contributing to best practice recommendations and swallow screening tool.	e- Delphi process	Quantitative and qualitative
Study 4 (chapter 6)	Usability of a swallow screening tool with MDT staff in non-specialised units to identify oropharyngeal dysphagia risk in acute CSCI patients	Pragmatic prospective observational feasibility study	Quantitative and qualitative

ii. Outline of the thesis

Within the thesis, chapter 2 provides brief details of the anatomy of the spinal cord and nature of CSCI, which helps to understand the physical context that influences swallowing function. This is followed by a review of the literature on CSCI and its impact on oropharyngeal dysphagia and respiratory function with details of existing clinical recommendations. Subsequent chapters represent each of four studies comprising of background, methods, results and discussion. The final discussion chapter will link the results of each study with the overall aims, detailing the implications of the findings and recommendations for future work.

The first study is reported in chapter 3 and presents the results of an online survey of usual clinical practices with CSCI patients by multi-professional ICU team members across specialised and non-specialised units. The results reflect differences in the management of impairments of swallowing, respiratory function, nutrition, oral hygiene and communication. It highlights variations in

practice across specialised and non-specialised units and between professional groups, indicating a need for further staff education and clinical recommendations.

The second study presented in chapter 4, provides unique insight into the lived experience of people with CSCI and oropharyngeal dysphagia through semi-structures interviews with eight participants and carers. They report lengthy delays to admission to a specialised unit alongside varied clinical input from staff in non-specialised unit. Using thematic analysis, common themes revealed despondency about not being able to eat or drink, challenges with being non-vocal with limited access to information reducing their ability to control their environment. Admission to a specialised unit provided greater opportunities for rehabilitation and staff support for planning for the future. With a paucity of data on the experience of prolonged admission in non-specialised units for people with CSCI, this study demonstrates the need for better staff awareness and early specialist intervention.

The third study, chapter 5, details the process of expert consensus to develop best practice recommendations in the absence of empirical evidence. This uses an electronic Delphi process with international multi-professional experts to generate consensus on the management of oropharyngeal dysphagia and its associated clinical issues. Using the agreed items, a swallowing screening tool was developed alongside best practice recommendations.

The fourth study reported in chapter 6, is a feasibility study to assess the usability of the swallow screening tool with multi-disciplinary staff in two non-specialised units with acute SCI admissions. Both units were major trauma centres (MTC) with existing SCI care pathways that included routine use of NG feeding and SLT referral for those with tracheostomy. Using the tool made decisions about oral intake occur earlier and more frequently and staff reported added value from the tool in highlighting risks of oropharyngeal dysphagia. Issues were highlighted with patient recruitment, staff engagement and documentation using the tool that would need to be addressed in a future study.

Chapter 7 discusses the findings of each of the linked four studies and their implications for the management of oropharyngeal dysphagia in CSCI patients. Limitations of each of the studies are discussed as well as proposed further areas of research and recommendations for clinical interventions for CSCI patients.

In summary, oropharyngeal dysphagia is known to have negative consequences in a number of neurological patient groups leading to pneumonia and malnutrition. CSCI patients, who have existing respiratory impairments, experience further compromise leading to prolonged ICU admission. The high burden to people with CSCI patients and the healthcare system have recently been recognised (Spinal Injuries Association, 2015), with a demand for early specialist intervention. The studies undertaken and reported in this thesis have contributed to the gap in the literature by identifying variations to the clinical management of CSCI patients across specialised and non-specialised units. As bed capacity in specialised units for respiratory patients is unlikely to change in the near future, this study proposes to improve the early identification and management of oropharyngeal dysphagia of CSCI patients in non-specialised units through development of a screening tool and best-practice recommendations. It is hoped that this will become embedded into routine care and facilitate earlier focussed interventions to improve outcomes for people with CSCI and oropharyngeal dysphagia.

2. The nature of cervical spinal cord injury and oropharyngeal dysphagia

2.1. Introduction

The ability to swallow allows ingestion of food, providing humans with a source of nutrition and pleasure from flavours and textures. Eating and drinking is also linked to cultural, religious and social interactions that are an important element in our society. Swallowing is a dynamic process that requires precise timing and coordination of the muscles of the oral cavity, nasopharynx, pharynx and larynx to ensure the airway is sealed during the swallow (Groher and Crary, 2015). This allows safe transit of food and fluid textures through to the oesophagus, avoiding entry into the airway (Logemann, 1998). Delayed timing, uncoordinated movements, or reduced strength can result in the airway remaining open and at risk of food or fluid being aspirated, which is a feature of oropharyngeal dysphagia (Groher and Crary, 2015).

As most of swallowing activity is covert, screening for oropharyngeal dysphagia aims to identify risk early to prevent secondary complications and direct the need for further detailed assessment (O'Horo et al., 2015). Diagnostic assessment identifies the swallow breakdown, which helps to plan suitable interventions to reduce the risk of oropharyngeal dysphagia and minimise complications (Bours et al., 2009). A number of screening tools have been developed, particularly for use with the stroke population where oropharyngeal dysphagia is a recognised risk to mortality (Martino et al., 2009, Edmiaston et al., 2010, Miles et al., 2013, Trapl et al., 2007). These will be discussed in further detail within this chapter. Despite the extensive development of screening tools, no universal method has been agreed (Bours et al., 2009, Kertscher et al., 2014). If oropharyngeal dysphagia is detected through screening and poorly managed, this is likely to compromise general health leading to long-lasting impact on morbidity and mortality (Singh and Hamdy, 2006, Altman, 2011, Ward and Morgan, 2009).

The empirical evidence on oropharyngeal dysphagia in CSCI is far less established. Studies are often retrospective with small sample sizes of patients with multiple complexities leading to contradictory findings on the factors causing oropharyngeal dysphagia (Abel et al., 2004, Kirshblum et al., 1999, Wolf and Meiners, 2003, Brady et al., 2004, Shem et al., 2011). The presence of tracheostomy, need for ventilation and surgical intervention are reported to have a link with oropharyngeal dysphagia in CSCI, but studies disagree on the impact of age, gender and level of injury. Despite this, all studies agree on the need for early oropharyngeal dysphagia identification, although specific clinical guidance has not been established to support a standardised process (National Spinal Cord Injury Strategy Board, 2012, Consortium for Spinal Cord Medicine, 2008). Recent evaluation of the skills used by clinicians to screen for oropharyngeal dysphagia in tracheostomy patients, reported varied and suboptimal skills, with a recommendation for use of a screening tool to aid the process (Ginnelly and Greenwood, 2016).

Patients with CSCI are expected to be managed in specialised units with staff familiar with the clinical issues expected. As this is now routine practice in many developed countries, clinical outcomes for CSCI patients managed in non-specialised units are rarely reported. Two studies identified variations to length of stay, functional recovery and social gains for SCI patients managed in specialised units compared to non-specialised units (New et al., 2011a, Smith, 2002). This has supported recommendations for admission to specialised spinal units for greater clinical expertise and consistency of interventions (Whiteneck et al., 2011, Bagnall et al., 2003, Jones and Bagnall, 2004). In the UK there are reports of up to 70% of SCI patients remaining in non-specialised units for extended periods of time waiting for a place at a specialised unit (personal communication from Medical Data Solutions and Services). Some patients do not receive any specialised rehabilitation and are reliant on care from staff in non-specialised units (Spinal Injuries Association, 2015). In the absence of

guidance on the clinical management of SCI patients it is not known what interventions are provided, especially for oropharyngeal dysphagia and whether a lack of specialised input has an impact on outcomes.

The next sections will briefly detail the anatomy of the spinal cord and impolications of injury to the cervical region. Following this will be a detailed review of the literature on oropharyngeal dysphagia in CSCI patients exploring the causes and clinical management. Further studies will explore surgical and respiratory interventions and their associations with oropharyngeal dysphagia. The impact of the clinical management of oral hygiene, communication and nutrition will be reviewed. Finally the reported risks of oropharyngeal dysphagia to morbidity and mortality will be discussed.

2.1.1 Spinal cord anatomy

In humans there are 31 vertebrae which protect the spinal cord and vary in shape and size to allow movements of flexion, extension, rotation and side bending (Chandar and Freeman, 2014). The spinal cord is a bundle of neuronal tissue that extends from the brainstem into the vertebral column and functions to transmit neural signals between the brain and the body as part of the central nervous system (Chandar and Freeman, 2014). Unlike the brain, the spinal cord has the grey matter centrally sited and surrounded by white matter, which contain the pathways to and from the brain. It has three major roles - the descending motor pathways maintain physical functions such as balance, muscle tone and visceral activity as well as voluntary movement; the ascending sensory pathways carry information about pain, touch, temperature from the limbs and trunk to the brain; the spinal reflexes are involuntary protective responses to external stimulation that allow the body to react quickly to a threat, bypassing the cerebrum and responding from the spinal cord level only (Diaz and Morales, 2016). The functions of the autonomic nervous system are dependent on intact spinal cord transmission to allow the balance of

sympathetic and parasympathetic responses to an environmental change, for example the fight or flight response or regulation of the heart (Karlsson, 2006).

There are 31 spinal nerve segments that extend laterally, providing motor and sensory innervation to specific parts of the body (Figure 2.1). These segments include 8 cervical, 12 thoracic, 5 lumbar and 5 sacral and one coccygeal (Chandar and Freeman, 2014). When describing the segments clinically, the named level is abbreviated by its initial letter and vertebrae number, for example thoracic level 8 is called T8.

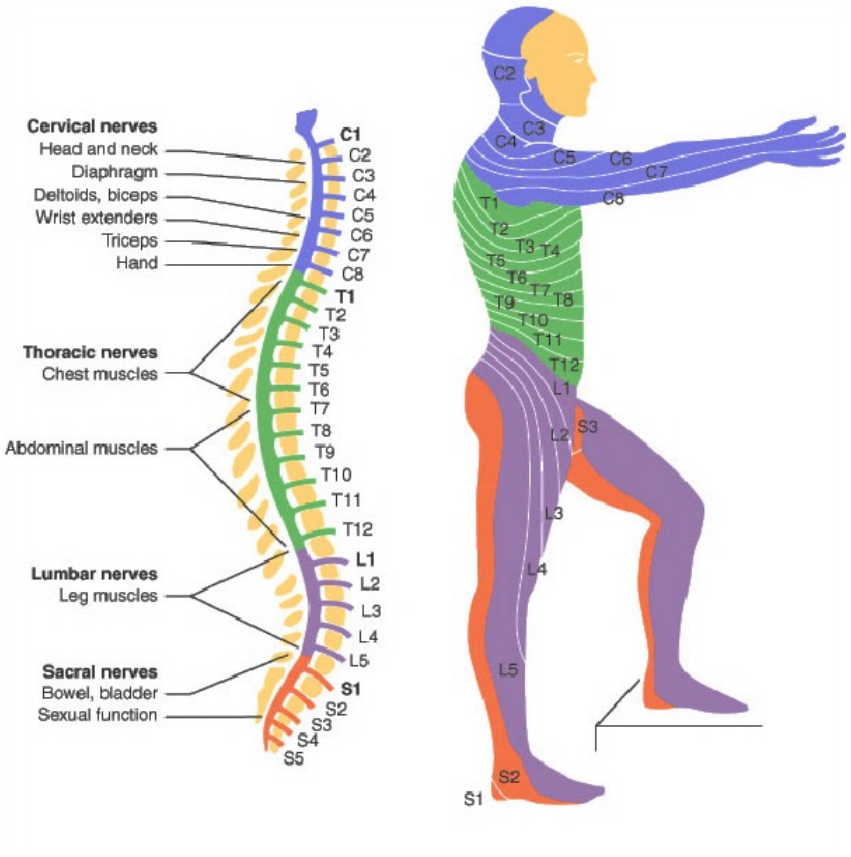

Figure 2.1 Spinal cord segments with associated motor and sensory innervation (*Source: http://thenextstepsci.org.au/)*

2.1.2 Cervical spinal cord anatomy

There are seven cervical vertebrae and eight cervical nerves, with C1 to C7 nerves exiting above the vertebrae and C8 exiting between the C7 and T1 vertebrae. The cervical vertebrae at C1 and C2 are referred to

as the upper cervical spine and have unique structures known as the atlas and axis to provide flexion and rotation of the head and neck. The remaining cervical vertebrae C3-C7 are known as the lower cervical spine and have similar structures. Of interest is their anatomical adjacency to the laryngeal structures of the thyroid cartilage at C4-C5 and cricoid at C6-C7 (Figure 2.2) (Ward and Morgan, 2009). The spinal cord at the cervical level is at its widest to accommodate a greater amount of ascending and descending tracts at C4 to T1 (Diaz and Morales, 2016). The cervical nerves at each level are responsible for motor control and sensation to a number of bodily functions, many of which are distal to the neck (Table 2.1).

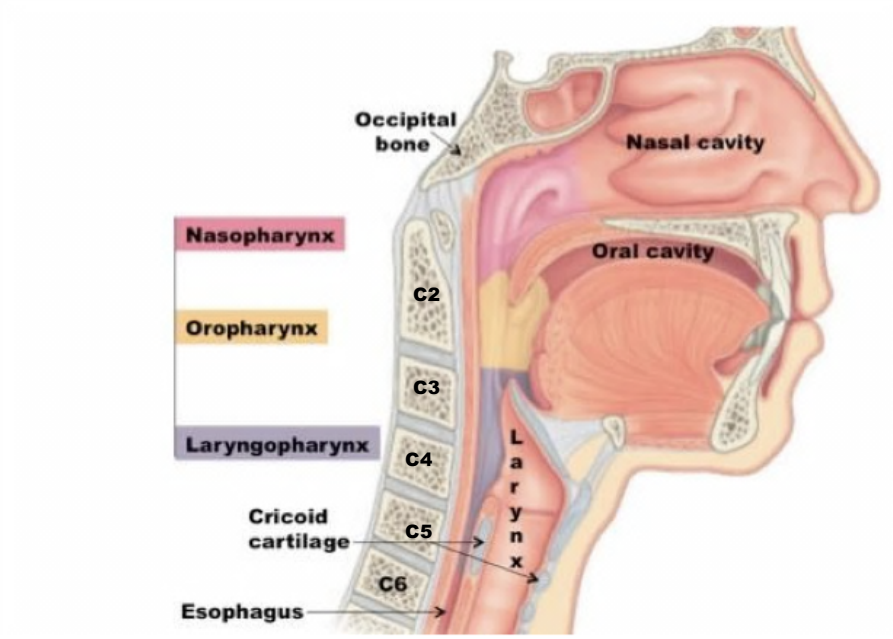

Figure 2.2 Cervical spine anatomy and adjacent structures
(used with permission from www.teachmeanatomy.com)

Table 2.1 Cervical spine levels and associated motor innervations

Cervical spine nerves	**Motor control**
C1 and C2	Head
C3 and C4	Diaphragm (breathing), shoulder shrug
C5	Biceps and deltoids
C6	Wrist extensors
C7	Triceps
C8	Hands and fingers

The majority of neurological innervations to the head and neck originate from the cranial nerves in the brainstem, however anastomoses with the cervical spinal nerves can occur creating the cervical plexus (Shoja et al., 2014). The cervical plexus is a network of nerves originating from the anterior rami of the cervical nerves C1-C4, each with a superior and inferior branch, except C1. These innervate the back and sides of the head and front of the neck. The phrenic nerve emerges from C4 and contains motor, sensory and sympathetic nerves supplying innervation to the diaphragm, important for breathing and pericardium functions. The ansa cervicalis is made up of the superior root of C1 and the inferior root of C2-C3, providing motor innervation to the geniohyoid, thyrohyoid, omohyoid, sternohyoid and sternothyroid. These muscles link the hyoid to other structures in the neck in order to stabilise and depress the hyoid during swallowing and speech movements. The hypoglossal nerve originates from the brainstem, and some of its fibres join with the ansa cervicalis at C1 to innervate the geniohyoid and thyrohyoid muscles before providing innervation to the tongue muscles. The tongue and palate are co-innervated by cranial nerves IX, X and XII independently of the spinal cord. This anastomoses of nerves may influence variability in loss of swallow function after SCI.

2.1.3 Spinal cord injury

A spinal cord injury (SCI) is a major traumatic event causing damage to the vertebral column and the cord within, subsequently impacting on multiple body systems (Grundy and Swain, 2002). Traumatic injuries are of sudden onset and severity, damaging the cord through either transection or penetration by a foreign body or bony fragments, due to a fall, road traffic accident, weapon injury or sports activity (Devivo, 2012). A non-traumatic injury occurs when a condition within the body, such as an infection, tumour or bleed causes compression of the cord (New et al., 2011b, Grassner et al., 2016). In either case, there are considered to be two processes affecting the pathology, firstly the injury causes mechanical cord damage and a secondly, a biochemical reaction to the

injury leading to widespread cell death, inflammation and a greater loss of neurological function (Oyinbo, 2011).

The resulting damage affects neural pathways within the spinal cord resulting in a loss of motor and sensory innervation from the level of injury and below. The American Spinal Injury Association (ASIA) developed a set of standards used internationally to classify the neurological impact of a SCI (Kirshblum et al., 2011). This includes motor testing of muscle strength at each spinal nerve level and sensory testing for light touch and pinprick sensations at each dermatome, repeated for each side of the body. The ASIA impairment scale (AIS) (Table 2.2) provides a prognostic evaluation of the degree of severity. This is now recognised as the gold standard assessment for all SCI patients. The ASIA assessment is completed by a trained doctor or physiotherapist (PT), ideally within 72 hours of injury. This helps to determine the level and severity of impairment and interventions required.

Table 2.2 ASIA Impairment Scale classification

A = Complete:	No sensory or motor function is preserved in sacral segments S4-S5
B = Incomplete:	Sensory but not motor function is preserved below the neurological level and includes sacral segments S4-S5
C = Incomplete:	Motor function is preserved below the neurological level and most key muscles below the neurological level have a muscle grade of less than 3
D = Incomplete:	Motor function is preserved below the neurological level and most key muscles below the neurological level have a muscle grade that is greater than or equal to 3
E = Normal:	Sensory and motor functions are normal

2.1.4 Cervical spinal cord injury

Injury to cervical level C5 or above will affect the phrenic nerve, paralysing the diaphragm and interrupting the normal breathing pattern.

This will necessitate an immediate need for respiratory support and tracheostomy insertion as the risk of death is high (Arora et al., 2012, McCully et al., 2014, Leelapattana et al., 2012, Seidl et al., 2010b). Lesions to levels C5-C8 will cause variable degrees of weakness to the intercostal and abdominal muscles leading to hypoventilation and weak cough and retained secretions (Galeiras Vazquez et al., 2013, Wong et al., 2012c). The combination of atelectasis (lung collapse) and poor secretion clearance increases the risk of pneumonia. Regular respiratory interventions are required to ensure effective secretion removal (Liebscher et al., 2015, Fishburn et al., 1990, Berlly and Shem, 2007). Gastrointestinal functions are affected by the loss of autonomic control, leading to dysmotility and paralytic ileus (Karlsson, 2006, Chung and Emmanuel, 2006), necessitating nasogastric tube insertion to aspirate gastric contents and deliver enteral feeding until gastric function returns (Thibault-Halman et al., 2011, Rowan et al., 2004). Injury to levels C1 to C7 will cause paralysis to the motor and sensory functions of the upper and lower body, including limbs, leading to tetraplegia necessitating full assistive care for the patient (Grundy and Swain, 2002).

Laryngeal and pharyngeal functions are largely innervated by the cerebral cortex and brainstem, so are not expected to be damaged following SCI (Diaz and Morales, 2016, Lindsay et al., 2010). However, several studies have reported cases of patients with damage to the complex network of nerves around the cervical spine, affecting the pharynx and larynx. Pollock et al. (1981) reported four unexpected cases of pharyngeal damage post CSCI, similarly, Grundy et al. (1984) detailed eight patients with cranial nerve injuries and oropharyngeal dysphagia following CSCI. In a 20 year retrospective of SCI cases, Hsu et al. (1987) identified 47 cases of glottic or tracheal stenosis causing oropharyngeal dysphagia and dysphonia. Although this represents a small minority of the SCI population the associated respiratory and medical complications make this a significant risk (Hsu et al., 1987).

2.1.5 Laryngeal functions

The larynx is innervated by the superior and recurrent laryngeal nerves, both branches of the vagus nerve (CN X) (Fregosi and Ludlow, 2014). It serves three main functions, primarily as the entrance to the airway with a protective cough reflex, secondly to allow phonation for speech and thirdly as part of a biomechanical system for swallowing, directing food and fluid towards the oesophageal entrance whilst preventing entry to the airway (Ludlow, 2005). These functions will be detailed further in the next section.

i. Breathing

The effective passage of air in and out of the lungs via the larynx is an essential life function and demands varying laryngeal postures (Marchal, 2010). During inspiration, the vocal cords abduct to allow air to pass through with minimal turbulence, whereas during swallowing complete closure of the larynx is required causing a brief apnoeic period (Fregosi and Ludlow, 2014). Studies on synchronised swallowing and breathing have revealed that normal adults swallow towards the end of the expiratory phase, before a short expiratory burst, thought to minimise the risk of accidental inhalation of food or fluid (Martin-Harris et al., 2005, Hiss et al., 2001).

The cough reflex protects the airway from potential irritants, foreign particles and aspiration triggered by sensory stimulation of the vagus nerve in the upper airway (Chang, 2006). Central control in the medulla transmits motor signals via the vagus, phrenic and spinal motor nerves to innervate the diaphragm, respiratory muscles and larynx to deliver a 3 phase event that involves a rapid inspiration, followed by vocal cord closure and compression of the respiratory muscles to build-up sub-glottic pressure (Polverino et al., 2012). Finally the glottis opens with a forced expiration to dislodge any irritant or foreign material from the lungs into the upper airway to either be swallowed or expectorated into the mouth (Polverino et al., 2012).

ii. **Phonation**

Rapid vibrations of the vocal folds called the Bernoulli effect, produce phonation by using a steady stream of expiratory airflow from the lungs, controlled by the diaphragm and respiratory muscles (Marchal, 2010, Mathieson, 2001). The vocal cords adduct and approximate at the glottis through adjustment to arytenoid positions controlled by the intrinsic laryngeal muscles. To maintain phonation, a pressure differential between subglottal and supraglottic pressure is required (Ludlow, 2005). Volume is controlled by changes in subglottal pressure and vocal fold tension whilst voice quality is affected by change in the structure of the vocal cords. The extrinsic muscles change the position of the larynx that influence pitch. All spoken languages have voiced and voiceless consonants that require precise and dynamic control of adduction and abduction whilst maintaining airflow through the glottis, which is thought to involve both automatic and volitional control (Ludlow, 2005).

iii. **Normal swallowing**

The process of swallowing has been divided into four stages: the oral preparatory stage, oral stage, pharyngeal stage and oesophageal stage (Figure 2.3) (Logemann, 1998, Groher and Crary, 2015). Each stage requires co-ordinated motor activity of the oral cavity, pharyngeal and laryngeal structures to ensure safe passage of the bolus to the oesophageal opening. Sensory stimuli such as tastes, touch, pressure and temperature, influence timing of the swallowing process (Steele and Miller, 2010).

The oral preparatory stage is under voluntary control with food and fluid held in the oral cavity by the lips forming an anterior seal. Meanwhile the teeth break down the food and the tongue helps to form a moist cohesive bolus. The trigeminal nerve (CN V) innervates the muscles of mastication, with the facial nerve (CN VII) maintaining lip and cheek compression to keep food from falling out of the mouth, whilst in an

upright position. As the bolus is pushed posteriorly through the oral cavity by the tongue, this signifies the oral stage, innervated by the hypoglossal nerve (CN XII). The soft palate creates a posterior seal to the nasal cavity to prevent any food entry, controlled by the vagus (CN X) and accessory nerves (CN IX). The pharyngeal stage is under involuntary or reflexive control as the bolus is propelled posteriorly by the tongue, passing the anterior tonsillar pillars, triggering a series of coordinated movements. The larynx elevates and tilts anteriorly, covering the laryngeal vestibule with the epiglottis, channelling the bolus along later channels of the larynx towards the open upper oesophageal sphincter (Groher and Crary, 2015). Additional airway protection is provided by closure of the true and false vocal cords, whilst the base of tongue propels the bolus through the pharynx. Normal variations to swallow timing exist with bolus size influencing temporal changes (Kendall et al., 2000). The bolus enters the oesophagus in the last stage of swallowing when the upper oesophageal sphincter relaxes and opens at the end of the pharyngeal stage. The bolus passes quickly towards the stomach assisted by gravity when in upright (Mashimo and Goyal, 2006) and a series of peristaltic waves of the striated upper oesophageal muscles and smooth lower oesophageal muscle. Motor innervation of the oesophagus is provided by the vagus nerve, whereas both the sympathetic and parasympathetic system innervate sensory information (Diamant, 2012, Mashimo and Goyal, 2006).

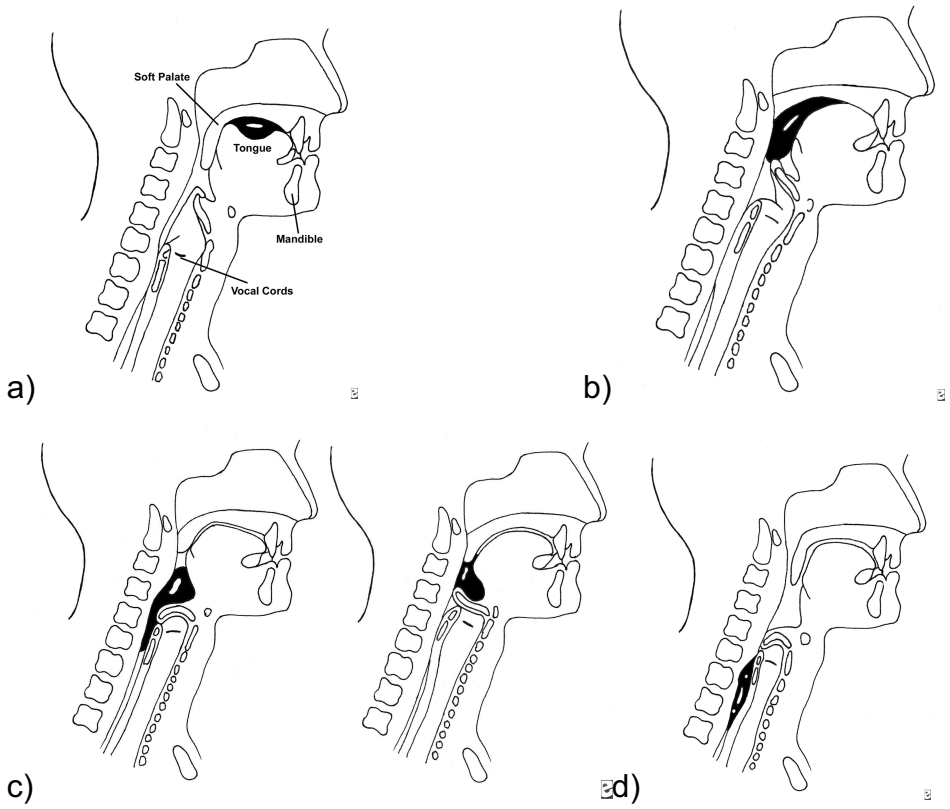

Figure 2.3 The stages of the normal swallow a) oral preparatory stage b) Oral stage c) pharyngeal stage d) oesophageal stage

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2.1.6 Identifying oropharyngeal dysphagia

Oropharyngeal dysphagia is defined as a dysfunction of swallowing, which ranges from poor oral control to pharyngeal residue and aspiration of food or fluids into the lungs (Groher and Crary, 2015, Logemann, 1998). At all levels this poses a risk to health, which is increased for patients with additional health conditions, such as progressive neurological disease or complex trauma (Steele and Cichero, 2014, Ward and Morgan, 2009, Altman et al., 2010). Preventing the complications of oropharyngeal dysphagia has been found to benefit patients and reduce healthcare costs (Cichero et al., 2009, Bonilha et al., 2014). Screening and assessing for oropharyngeal dysphagia have been described as two separate processes, often undertaken by different professionals (Perry and Love, 2001).

Screening is an informal process to identify risk of oropharyngeal dysphagia and carried out by trained front-line staff (Kertscher et al., 2014) . Assessment is usually led by a SLT to specify the nature and severity of the disorder and develop an intervention plan. This section will review the current processes employed by healthcare staff to screen and assess oropharyngeal dysphagia across patient populations.

i. **Screening**

Screening for the signs of oropharyngeal dysphagia is usually undertaken by non-speech and language therapy staff to identify the risk of aspiration and prevent the development of pneumonia and other health complications (Cichero et al., 2009). Screening primarily involves an evaluation of oral-motor movements, followed by trials of food and fluid to identify the presence of aspiration indicated by coughing or choking behaviour (Trapl et al., 2007, Cichero et al., 2009, Martino et al., 2009). As such, it is usually a pass/fail process and does not provide any detailed information on swallow physiology (Ward and Morgan, 2009). For those who pass, they can proceed with oral intake whilst those who fail need for further comprehensive swallowing assessment (O'Horo et al., 2015).

The validity of a number of screening tools for use with neurological patients were compared to the gold standard assessments of FEES and VFS (Bours et al., 2009, Kertscher et al., 2014). The sensitivity for screens testing with water ranged from 27% to 85% and specificity from 50% to 88%. Screens using a range of consistencies had a range of sensitivity from 41% to 100% and specificity from 57% to 82%. Methodological flaws were reported for many studies, which limited further meta-analysis. A recent comprehensive systematic review reported on screening tools across patient groups from 48 studies (O'Horo et al., 2015). Each tool was compared to either VFS or FEES assessments and demonstrated great heterogeneity with overall low sensitivity and specificity for identification of aspiration, oropharyngeal

dysphagia and pneumonia. This makes the selection of a single screening tool a challenge for a specific patient group, such as SCI.

National guidance has mandated swallow screening for all stroke patients within four hours of admission (Royal College of Physicians and Intercollegiate Stroke Working Party, 2016). Oropharyngeal dysphagia incidence in stroke is between 40 and 78% with poor clinical outcomes and increased risk of pneumonia when not identified early (Martino et al., 2005). Patients are not allowed to eat until the safety of swallowing is evaluated. Despite this no specific screening tool has been recommended and little agreement on the volume, textures or clinical indicators required for stroke patients (Daniels et al., 2012). For critically ill patients, there are no recommendations for screening prior to oral intake due to a lack of supporting evidence (National Institute for Health and Clinical Excellence, 2009). A brief review of screening tools for stroke patients will follow, to explore their use and suitability for CSCI patients.

Systematic reviews of the utility of a number of tools have been reported to demonstrate their variety and limitations (Speyer, 2013, Schepp et al., 2012). The Acute Stroke Dysphagia Screen (Edmiaston et al., 2010) is a simple screen designed to be administered by nursing staff and requiring little training. It consists of four questions regarding the patient's level of consciousness, facial, tongue and palatal asymmetry. If these are passed, the nurse progresses onto giving a 3oz water test, monitoring for voice changes or cough. If any feature is present, this is indicative of oropharyngeal dysphagia and a reduction in level of consciousness contributes to aspiration risk. When compared with a clinical bedside assessment, the Mann Assessment of Swallowing Ability (MASA) (Mann, 2002) showed 91% sensitivity and 74% specificity for detecting oropharyngeal dysphagia and 95% sensitivity and 68% specificity for aspiration risk. However, it relies on signs of coughing, choking and voice change as indicative of oropharyngeal dysphagia and an absence suggests no difficulties allow the patient to eat and drink.

The Toronto Bedside Swallowing Screening Test (TOR-BSST) (Martino et al., 2009) attempts to be predictive of oropharyngeal dysphagia in stroke patients at both the acute and rehabilitation stage through a 2-step process administered by trained nurses. Firstly, voice and tongue movement are checked for signs of abnormality, secondly, teaspoons of water are given in increasing amounts and voice checked again for signs of wetness, suggestive of aspiration. They report 91% sensitivity and 67% specificity across all patients, and 96% and 64% respectively for acute patients. Both the MASA and TOR-BSST screening tools rely on signs of cranial nerve impairment to determine the presence of oropharyngeal dysphagia and coughing following water intake to indicate aspiration. These tools are unable to estimate oropharyngeal dysphagia or aspiration in patients without cranial nerve impairments or for those with a tracheostomy, that prevents an evaluation of cough and voice production (Brodsky et al., 2016).

To date there are no published validated screening tools for use with tracheostomy patients, despite recent recommendations for routine oropharyngeal dysphagia screening for these patients following the recent report on tracheostomy care by the National Confidential Enquiry into Patient Outcomes and Death (2014). Silent aspiration is known to be a high risk for those with respiratory compromise and tracheostomy (Leder, 2002). For this reason, cautions have been stated against using water testing for oropharyngeal dysphagia, although alternative methods have not been identified (Leder et al., 2012). SLTs are known to use both formal and informal methods of oropharyngeal dysphagia screening for tracheostomy patients although only 25% consider their methods to be effective (Ginnelly and Greenwood, 2016). The Modified Blue Dye Test (MBDT) has been described as an inexpensive and simple test of aspiration in patients with tracheostomy. It requires food and drink trials to be dyed with blue food colouring and then given to the patient after which they are suctioned via the tracheostomy for evidence of blue aspirated material (Belafsky et al., 2003). Since then studies have correlated blue dye tests with simultaneous instrumental

assessments and questioned specificity and sensitivity (Brady et al., 2015, O'Neil-Pirozzi et al., 2003). A recent systematic review of six studies reported low specificity but high sensitivity to exclude aspiration however a high risk of false negatives make this method unreliable for clinical practice (Béchet et al., 2016). Currently there are no screening tools for evaluating risk of oropharyngeal dysphagia in tracheostomy patients and a lack of consistency that prevents identification for further diagnostic assessment.

ii. **Assessment**

The routine method of assessment carried out by SLTs is called a bedside or clinical swallow evaluation (BSE or CSE), whereby a sensorimotor assessment is made of the patient's mouth, lip and tongue movements, followed by swallowing trials of water or food textures for detection of coughing and voice change to indicate aspiration (O'Horo et al., 2015). However, like the screening tests, BSE is not sensitive to detecting oropharyngeal dysphagia and silent aspiration, which require instrumental assessments (Brodsky et al., 2016, Leder, 2015, Bours et al., 2009, Kertscher et al., 2014).

The key instrumental assessments recognised as gold standard for diagnosis, are VFS and FEES (Speyer, 2013, Brady and Donzelli, 2013). Videofluoroscopy (VFS) is a non-invasive assessment involving video x-ray of the swallowing process from mouth to oesophagus, using barium coated food trials for visual contrast (East et al., 2014). Fibre-optic endoscopic evaluation of swallowing (FEES) is an invasive assessment using a nasendoscope with a light source passed through the nose to view the laryngeal and pharyngeal structures which are viewed on an external screen (Langmore, 2003). Both assessments are recorded for detailed study and reporting. VFS looks at timing and co-ordination of every stage of swallowing with a particular focus on airway protection and aspiration. The study often requires the patient to sit or stand in an upright position for an extended period in an X-ray suite, whilst each food textures is given to the patient and effective strategies trialled to minimise any swallowing difficulties (Martin-Harris et al.,

2000). In contrast, FEES can take place at the patient's bedside in any physical position required. Although the oral stage cannot be viewed, laryngeal anatomy and function can be assessed before food trials are given. Normal food samples permit evaluation of pharyngeal swallow effectiveness through observation of patterns of impairment, texture residue and responses to penetration and aspiration of food such as cough (Langmore, 2001).

To determine the optimal swallowing assessment for tracheostomy patients, results of bedside assessment and FEES for 25 patients were compared (Hales et al., 2008). This demonstrated a negative predictive value of 64% indicating that in over a third of cases, FEES found an abnormality, which was not identified at bedside. This was particularly evident for silent aspiration. Another study, compared clinical evaluation with FEES and VFS in 21 recently extubated patients (Noordally et al., 2011). Cough was found to be a reliable indicator except for those with silent aspiration, which was better identified with either FEES at 24 hours or VFS at 48 hours. These studies support the use of instrumental assessment to identify laryngeal pathologies and particularly silent aspiration, which is a feature for tracheostomy and ventilated patients.

The following section will review the literature search specific to oropharyngeal dysphagia in CSCI and associated challenges.

2.2. Literature Search

The need for an extensive literature search was motivated by clinical experience of working with CSCI patients with oropharyngeal dysphagia, who had experienced a lack of oropharyngeal dysphagia care by healthcare staff in non-specialised units. Oropharyngeal dysphagia was not routinely recognised or detected in CSCI patients resulting in poor clinical decision-making following symptoms of oropharyngeal dysphagia leaving patients nil by mouth for extended periods or intermittently eating and experiencing repeat chest infections.

This led to queries about the signs and symptoms of oropharyngeal dysphagia following CSCI and the optimal clinical management required. The surgical and respiratory interventions were identified as contributing factors in the literature however, the impact of the SCI is unclear. The review that follows investigates the reported effects of surgery, tracheostomy and ventilation on laryngeal function, which helps to understand the impact on swallowing function. Further review of the clinical management of oral hygiene, communication and nutrition may highlight existing clinical guidance for CSCI patients to minimise secondary complications. Finally, the link between oropharyngeal dysphagia, its potential contribution to pneumonia and mortality will be explored.

The literature review attempts to answer the following research questions:

1. What are the causes of oropharyngeal dysphagia in CSCI?
2. What impact do the secondary interventions for CSCI, namely, tracheostomy, ventilation and surgery, have on swallowing function?
3. How are nutrition, oral hygiene and communication managed in those with CSCI and oropharyngeal dysphagia?
4. Is there a link between oropharyngeal dysphagia, pneumonia and mortality in CSCI?

A PICO model was used detailing the specific interventions and outcomes for those with acute CSCI using the search terms detailed in Table 2.4.

Patient/population	**Intervention**	**Outcomes**
spinal cord injury; cervical; tetraplegia; quadriplegia	Artificial respiration; mechanical ventilation; tracheostomy	Oropharyngeal dysphagia; aspiration pneumonia; ventilator associated pneumonia; communication; mortality
	Cervical spine surgery; posterior; anterior	
	Enteral nutrition; nasogastric; gastrostomy	
	Oral hygiene; mouthcare; xerostomia	

Table 2.3 PICO table of search terms

Keyword and Medical Subject Heading (MeSH) searches were used with the following databases: Medline, CINAHL, EMBASE, PsycInFO and Web of science. Further hand searches were made of reference lists of retrieved articles, grey literature and conference abstracts. Papers were excluded that dealt with other neurological impairments, degenerative conditions and chronic SCI. Searches were limited to adult humans and studies published in English.

2.2.1 Epidemiology of SCI

SCI is recognised as a rare event with devastating consequences, however poor data recording has made an estimation of incidence in UK difficult. A global annual incidence of 23 per million population was estimated in a worldwide review of SCI trauma incidence (Lee et al., 2014). For Western Europe a median annual incidence of 16 per million is estimated of which 49% are recorded as cervical level injuries. The USA have several SCI registries that estimate the incidence of new traumatic SCI cases at 40 per million (Devivo, 2012) with injuries to the cervical level accounting for over 50% of all injuries. No recent data had been available for the UK. Grundy and Swain (2002) estimated that 10 to 15 per million population experience a traumatic SCI per year in UK, with 40,000 people living with the condition. A more recent retrospective review of both trauma and non-trauma SCI admissions to a SIU in Glasgow over 20 years, reported changing demographics and an increased incidence of 17 per million due to an aging population (McCaughey et al., 2016). Over 60% had cervical level injuries due to falls, of which 31% were at levels C1 to C4, requiring long-term ventilation.

Life expectancy for those with CSCI has been reported to be significantly lower than normal, with increased age being a prognostic factor (DeVivo et al., 1992). Deaths from respiratory dysfunction are a leading cause with a 7% increase in mortality for every increased year of age at injury (Frankel et al., 1998). For those over 60 years mortality increases to 15% at 1 month post injury and 50% at one year, with

pneumonia as the main cause of death (Prusmack et al., 2006). Life expectancy can be improved with good respiratory care and management of aspiration for those with CSCI (Shavelle et al., 2006).

The next section will review the literature on the link between CSCI and oropharyngeal dysphagia, reporting on the population features, methods of screening, identified causes and complications.

2.2.2 Epidemiology of CSCI and oropharyngeal dysphagia

The presence of oropharyngeal dysphagia post-CSCI has been detailed in less than ten studies worldwide with sample sizes varying from 42 to 175. Using different cohorts, outcome measures and screening methods the reported incidence ranges from 8% to 80% (Wolf and Meiners, 2003, Shin et al., 2011) (Table 2.5). All cases were linked to cervical level injuries, often requiring tracheostomy and ventilation. The data in these studies were limited to participants admitted to specialised units limiting estimation of wider population prevalence. A wide age range was reported across the studies, with the mean age in most studies being the early 40's and one larger study reporting a mean age of 55 years (Brady et al., 2004) (Table 2.5). Male to female ratios tended to be high, except in one study that featured more females (Brady et al., 2004), due to inclusion of non-traumatic injuries, such as spinal cord infections or lesions.

Table 2.4 Summary of studies reporting oropharyngeal dysphagia following CSCI

Authors	Study site and period of assessment	Inclusion criteria	Stud y size (n)	Mean age (range); M:F	Screen and assessment tools	Dysphagia incidence %	Correlating factors	Recommendations
Kirshblum et al.1999 (R)	on admission to rehabilitation unit	Acute traumatic SCI	42	44.3 (15-86) 5:1	BSE, MBT, VFS	22.50%	Age, tracheostomy, ventilation, anterior cervical surgery	Early diagnosis
Wolf & Meiners 2003 (P)	within 3 months of admission to spinal unit	Acute cervical lesion	51	43.4 (16-89) 2.2:1	FEES	80%	Brainstem lesions, NOT age or level, anterior surgery	Early treatment
Brady et al. 2004 (R)	on admission to two rehabilitation units	All cervical injuries (trauma and non trauma)	131	55.6 (17-87) 1:1.2	BSE, VFS/FEES	55%	Tracheostomy, cervical spinal surgery, brain injury	Identify dysphagia using predictive factors
Abel et al.2004 (P)	on admission to spinal unit	Cervical SCI	73	42.9 (0.57-86.8) 2.3:1	Question-naire, MBT, VFS	44%	High cervical and complete injuries, tracheostomy	Early detection and monitoring
Seidl et al. 2010 (R)	Within 8 weeks of admission to trauma centre	C0-C8	175	43.45 (14-89) 4.6:1	BSE + FNE	16%	Level of paralysis, tracheostomy, ventilation, other injuries	SLT assessment pre-oral feeding, FNE if dysphagia is suspected
Shin et al. 2011 (R)	Inpatients admitted to spinal unit	All tetraplegic patients	121	44.93 (9-78) 6.6:1	VFS	8%	Age, tracheostomy, dysphagia signs	Monitor for signs of aspiration
Chaw et al. 2012 (P)	Within 32 days of admission to spinal unit -	Acute CSCI	68	43 (range not given) 5:1	BSE and VFS within 72hrs	30.90%	Ventilation, tracheostomy, NG, age	Need good pulmonary management
Shem at al. 2012 (P)	All admissions to spinal unit	Acute tetraplegia	40	41 (23.5-68.7) 3.4:1	BSE and VFS	40% based on BSE; 44% on VFS, 14.8% with aspiration	Age, tracheostomy, ventilation and NG tube	Early screening of all tetraplegic patients

(R)=retrospective, (P)=prospective, MBT =modified blue-dye test, VFS=videofluoroscopy, FEES=fibreoptic endoscopic evaluation of swallowing, BSE=bedside swallow evaluation, FNE=flexible nasendoscopic evaluation

2.2.3 Oropharyngeal dysphagia screening and assessment in CSCI

A key issue with the reported studies in Table 2.5 is the variable definition of oropharyngeal dysphagia. Most studies used aspiration as the key sign to determine the need for further instrumental assessment (Shem et al., 2012a, Chaw et al., 2012, Shin et al., 2011, Seidl et al., 2010a, Brady et al., 2004, Wolf and Meiners, 2003, Kirshblum et al., 1999). BSE was used in over 60% of studies to determine the need for further assessment. However, as silent aspiration cannot be detected through this screen this may have led to the variability in reported incidence (Kirshblum et al., 1999). These issues were highlighted in the study by Shin et al. (Shin et al., 2011) where all participants were interviewed about signs and symptoms of oropharyngeal dysphagia prior to a VFS. Of 10 participants identified with aspiration, four had no reported symptoms and of those two had no signs. They cautioned about the risks of silent aspiration leading to increased complications. Overall, they reported an 8% incidence of aspiration although 53.7% of their cohort demonstrated difficulties at the pharyngeal phase of swallowing.

Four studies described oropharyngeal dysphagia in terms of disruption to food transit, occurring independently of aspiration (Wolf and Meiners, 2003, Brady et al., 2004, Abel et al., 2004, Shin et al., 2011). Wolf and Meiners (2003) focussed solely on laryngeal function, detailing five levels of impairment that included oedema, cough and swallow reflex. Pharyngeal phase disruptions were commonly identified (Abel et al., 2004, Shin et al., 2011) with a description of the presence or absence of pharyngeal residue (Brady et al., 2004). These studies provide strong evidence of pharyngeal and laryngeal disruption that may not be detected by bedside screening. The use of instrumental assessments in these studies provides further diagnostic details about the nature of oropharyngeal dysphagia in CSCI.

In six studies the follow-up use of VFS or FEES was based on the outcome of a screening questionnaire or BSE (Kirshblum et al., 1999, Brady et al., 2004, Abel et al., 2004, Seidl et al., 2010a, Chaw et al., 2012, Shem et al., 2012a). As

described earlier, these methods of screening may not be sensitive to silent aspiration so participants with these features would not be selected for further investigation. Participants requiring VFS would need to tolerate sitting upright and transportation to radiology, which may be an issue for those with CSCI. FEES is an investigation that offers greater access when carried out at bedside, usually by SLT. Only one study used this solely (Wolf and Meiners, 2003) and another offered it as an alternative to VFS (Brady et al., 2004). Both these studies reported higher incidences of oropharyngeal dysphagia (80% and 55% respectively). A further study used flexible nasendoscopy (FNE) administered by an ENT consultant following SLT screening using BSE (Seidl et al., 2010a). A far lower incidence of 16% was reported although this focussed only on presence of penetration and aspiration rather than features of oropharyngeal dysphagia.

Using a sensitive screening tool and appropriate assessment for oropharyngeal dysphagia provides greater information on the breakdown of swallowing in CSCI. This allows specific interventions to be planned to reduce the risk of complications. Having information on swallowing dysfunction also helps to determine prognosis for recovery and the need for other clinical interventions, such as nutritional support. To understand the causes of oropharyngeal dysphagia in CSCI, the cited studies have sought to identify contributing factors in the absence of cortical disruption.

i. **Causes**

Identifying the causative factors for oropharyngeal dysphagia in CSCI was a theme in many of the studies in Table 2.5, with the aim of supporting early swallow screening. These conclude that multiple co-morbid factors had a significant correlation with oropharyngeal dysphagia (Kirshblum et al., 1999, Shin et al., 2011, Seidl et al., 2010a). This includes older age, level and severity of injury, presence of tracheostomy and additional multiple injuries. Higher cervical injuries are linked to an increased need for respiratory interventions and thought to be predictive of oropharyngeal dysphagia (Kirshblum et al., 1999, Abel et al., 2004). Almost all studies identified tracheostomy alone as a primary factor for oropharyngeal dysphagia (Kirshblum et al., 1999, Seidl et al., 2010a, Brady et al., 2004, Abel et al., 2004, Shin et al., 2011, Chaw et al., 2012). The

need for ventilation was another strongly linked factor (Kirshblum et al., 1999, Seidl et al., 2010a, Chaw et al., 2012). Only two studies reported spinal surgery to be a positive factor (Kirshblum et al., 1999, Brady et al., 2004) with three studies stating no identified link (Abel et al., 2004, Seidl et al., 2010a, Shin et al., 2011).

Variations to study methodology, sample selection, and size limit the applicability of results. Half the studies were retrospective and reported small incidence rates. This may be due to local selection of assessments not sensitive to silent aspiration or the inclusion of participants with less severe injuries who survive and gain admission to a specialised unit. Despite the variations, evidence from the literature is consistent in suggesting multi-factorial causes to oropharyngeal dysphagia in CSCI. In turn, each of these factors will be considered in terms of their contribution to swallowing dysfunction.

ii. Complications of oropharyngeal dysphagia

All the studies detailed above recommend early oropharyngeal dysphagia identification and management in order to reduce the complications of oropharyngeal dysphagia. This was primarily considered to be aspiration, although measured in terms of impact on respiratory function and nutrition (Shin et al., 2011, Brady et al., 2004). Aspiration is known to result in reduced respiratory function with an increased risk of pneumonia and mortality (Liebscher et al., 2015, Grossman et al., 2012, Arora et al., 2012). The presence of tracheostomy and need for ventilation masks the complexity of laryngeal and pharyngeal dysfunction making causation unclear (Abel et al., 2004, Shin et al., 2011, Chaw et al., 2012, Shem et al., 2012a).

A further consequence of oropharyngeal dysphagia is an increased risk of malnutrition as oral intake is reduced and becomes unsafe (Benfield and Michou, 2016). For SCI patients with varied metabolic needs, using non-oral methods, such as nasogastric or gastrostomy feeding were often linked to those with oropharyngeal dysphagia (Wolf and Meiners, 2003, Abel et al., 2004, Chaw et al., 2012, Shem et al., 2012a). The combination of respiratory and nutritional difficulties for those with oropharyngeal dysphagia increases patients' morbidity

and demands increased interventions to reduce the impact (Brady et al., 2004, Kirshblum et al., 1999).

Having considered the causes and complications of oropharyngeal dysphagia in CSCI in the cited studies, the next section is a review of the wider literature on SCI clinical management. This will examine the impact of respiratory and surgical interventions on swallowing function and the effective management of secondary complications for those with oropharyngeal dysphagia, namely oral hygiene, communication and nutrition.

2.2.4 Respiratory interventions following CSCI

Injuries to the cervical spine result in a loss of innervation to the respiratory muscles. Paralysis of the diaphragm, abdominal and intercostal muscles affect inspiratory and expiratory muscle functions and effective gas exchange (Schilero et al., 2009). Autonomic dysfunction results in hyper-secretion, which together with reduced cough increases secretion retention. This is a leading cause of chest infections and pneumonia in CSCI (Brown et al., 2006). Respiratory interventions need to be immediate to provide 24-hour respiratory support and chest clearance using tracheostomy and mechanical ventilation (Berney et al., 2011a, Wong et al., 2012c).

i. Tracheostomy

Variations have been reported in the optimal timing and need for tracheostomy in CSCI patients (Table 2.6). Twenty-five years ago, the incidence of tracheostomy was 11.2% with a 30% mortality rate due to respiratory complications (Biering-Sorensen and Biering-Sorensen, 1992). Changes in the respiratory management of SCI patients have demonstrated a positive impact on mortality rates, with those with ASIA scores of A and B reporting a 16.7% and C1-C4 10.5% (Martin et al., 2011). More recent incidences of tracheostomy insertion ranges between 49% and 81% especially for those with injuries C5 and above or complete injuries, and has been associated with greater survival and improved outcomes (Harrop et al., 2004, Como et al., 2005, Wallbom et al., 2005). Access to chest secretions via tracheostomy suction provides effective clearance of the lungs in the absence of effective cough, reducing chest

infections (Fishburn et al., 1990, Arora et al., 2012). Predictive factors have been proposed to aid decision-making for tracheostomy placement. A large data review of CSCI admissions determined five independent predictors for tracheostomy need (Branco et al., 2011). Clinicians must consider the need for early intubation, Injury Severity Score of 16 or more (Baker and O'Neill, 1976), diagnosis of complete CSCI, presence of facial fracture or thoracic trauma. Each of these represents mechanical or neurological disruption to the respiratory system. Level of injury above C4 was not included as a significant factor, despite others considering this to be predictive of need for tracheostomy (Childs et al., 2015, Jones et al., 2015).

Once the need for tracheostomy is established, the timing of insertion should be considered. This remains a contentious issue especially for high cervical injuries with concerns that early tracheostomy may compromise survival, particularly in proximity to spinal surgery (Berney et al., 2008). The delay in tracheostomy is also driven by the possibility that respiratory function may improve following resolution of spinal shock and tracheostomy may not be required (Liebscher et al., 2015). In a number of studies, tracheostomy insertion within 7 days has been found to be optimal by reducing the impact of secretion retention and delivering effective ventilation from an early stage, stabilising the respiratory system (Como et al., 2005, Ganuza et al., 2011, Romero et al., 2009, Leelapattana et al., 2012). In contrast late tracheostomy is associated with increased respiratory complications, morbidity and mortality (Romero et al., 2009, Ganuza et al., 2011). Patients with low cervical injuries below C4 need respiratory monitoring to detect any disruption especially in the acute stages. Several studies report respiratory complications in those with injuries below C4, increasing the risk of pneumonia and increasing the need for tracheostomy at least in the early stages (Liebscher et al., 2015, Hassid et al., 2008, Leelapattana et al., 2012). Significant benefits of early insertion include reduced length of stay, respiratory complications and mortality (Leelapattana et al., 2012)

Table 2.5 Summary table of studies reporting tracheostomy incidence and respiratory interventions in CSCI patients

Author	Study period and site	Inclusion criteria	Study size (n)	Mean days from injury to tracheostomy (range)	Tracheo-stomy %	Weaning method	Reported complications	Recommendations
Biering-Sorensen et al. 1992 (R)	1968-1987; rehabilitation unit	Traumatic SCI – all levels. Cervical level=16%	600	Median 4.4 (0-48)	11.2%	-	Bleeding, pneumonia, pneumomedia-stinum	Early use of mini-tracheostomy to prevent complications such as swallowing
Harrop et al. 2004 (R)	6 years; spinal unit	Complete CSCI	178	7 (2-19)	69%	-	Pulmonary complications	Early tracheostomy in high risk patients
Como et al. 2005 (R)	2000-2002; Level 1 trauma centre	Acute CSCI	119	10 (1-27)	81%	-	NR	Early intubation and tracheostomy especially for those C5 and above
Wallbom et al. 2005 (R)	1998-2002; rehabilitation units	C1-C4	68	NR	49%	-	Pulmonary infections	Early respiratory intervention using a team approach
Hassid et al. 2008 (R)	1988-2004; Level 1 trauma centre	Traumatic SCI C5-T1	186, divided into complete SCI (n=108) and incomplete SCI (n=78)	NR	69%; Complete SCI-75%; Incomplete SCI – 50%	-	Pneumonia (67% complete CSCI, 24% incomplete)	Early respiratory evaluation for low cervical SCI. Early intubation for complete SCI.
Atito-Narh et al. 2008 (R)	12 years; spinal unit	Patients ventilated for >21 days	126	NR	NR	Vital capacity measures, slow wean, cuff deflation	Respiratory infections	Weaning in a specialised unit
Romero et al. 2009 (R)	2004-2007; ICU admission	Traumatic SCI C3 and below with tracheostomy in-situ	152, split into early (days 0-7) and late tracheostomy (day 7+)	NR	100%	-	Bleeding, stoma infection, suture dehiscence, granuloma, tracheal stenosis	Higher complication rate in late tracheostomy group

Berney et al. 2011 (P)	2004-2009; Admission to 3 ICUs	All CSCI patients requiring intubation or ventilation	114	NR	59.7%	-	Pulmonary secretion retention, inadequate cough	Early identification of need for tracheostomy
Branco et al 2011 (R)	2002-2006; National Trauma databank	Data on all CSCI admissions	5265	NR	20.6%	-	Five independent predictors for tracheostomy need: early intubation, complete CSCI, ISS ≥16, facial fracture, thoracic trauma.	Use of predictors to assess need for tracheostomy early.
Ganuza et al. 2011 (R)	2006-2009; admission to spinal unit	All cervical and thoracic injuries without prior tracheostomy	323, split into early tracheostomy (days 0-7) and late tracheostomy (day 7+)	NR	91.9%	-	tracheoesophageal fistula, mediastinal abscess, bleeding, infection	Early tracheostomy is safe. Percutaneous methods are preferable
Leelapattana 2012 (R)	1991-2010; Level 1 tertiary centre	Acute CSCI C4-C7 admitted within 24 hours of injury	66	12 ± 10 (NR)	62%	-	Pulmonary complications	Early tracheostomy in high risk patients
Wong et al. 2012 (R)	2 years; spinal unit	C1-C4	24	NR	NR	High tidal volume ventilation, High frequency percussive ventilation, insufflation - exsufflation	Dysphagia	Respiratory complications need recognition and management
Kornblith et al 2013 (R)	2005-2009; 14 trauma centres	SCI patient requiring ventilation	360	NR	43.3%	-	VAP, prolonged mechanical ventilation	Tracheostomy increases risk of morbidity and use needs consideration

Roquilly et al. 2014 (R)	2001-2009; 3 ICUs	Acute traumatic SCI	164	-	-	-	Pneumonia, atelectasis, tracheostomy	Prevention of pneumonia and atelectasis important for respiratory function
Childs et al 2015 (R)	2007-2013; Level 1 trauma centre	Cervical level injury	383	NR	15.4%	-	subcutaneous emphysema, pneumothorax, hematoma, wound infection, recurrent laryngeal nerve damage	ASIA impairment Scale A predicts need for tracheostomy
Liebscher et al. 2015 (R)	2004-2010; spinal unit	Acute traumatic CSCI C4-C8	37	8 ± 4	78%	-	Pneumonia	Optimised respiratory function in first 4 weeks
Jones et al. 2015	1998-2012; Level 1 trauma centre	Traumatic cervical level injury	163, split into complete and incomplete injury	Complete: before day 7 – mean 4.6, after day 7 – mean 11.7; Incomplete: total hospital days before day 7- 43, after day 7 - 44	50.3%	-	Respiratory failure, pneumonia	Factors determining need for tracheostomy: complete SCI, anatomic level of injury, Glasgow Coma Score, Injury Severity Score, associated thoracic injury

(R)=retrospective, (P)=prospective, NR=not reported, ISS=Injury Severity Score, VAP=ventilator associated pneumonia, LOS=length of stay

ii. **Ventilation, weaning and decannulation**

Respiratory failure in CSCI occurs as a result of muscle paralysis changing lung compliance together with increased secretion retention that restricts effective airflow (Berney et al., 2011a). Vital capacity is recognised as a clinical measure of respiratory function that has been linked to the level and severity of CSCI (Galeiras Vazquez et al., 2013). This measure has been described as a key predictor of need for tracheostomy as it represents respiratory muscle fatigue (Yugue et al., 2012, Galeiras Vazquez et al., 2013). National UK guidance for SCI weaning recommends the use of VC as an outcome measure in weaning trials to detect signs of respiratory fatigue which lead to weaning failure (Respiratory Information for Spinal Cord Injury, 2012).

Early respiratory management attempts to restore normal airflow to the lungs allowing effective gas exchange to continue, without which death will occur. The presence of complications listed in Table 2.6 increase the duration of ventilation required and attempts to reduce these are encouraged (Wong et al., 2012c, Roquilly et al., 2014, Wallbom et al., 2005). The lack of protocol to manage respiratory impairments in CSCI results in mixed practices, especially in non-specialised units (Liebscher et al., 2015, Wong et al., 2012c). A systematic review of acute respiratory management in CSCI identified the need for a clinical pathway with consistent respiratory interventions that include tracheostomy and ventilation, for effective management of complications (Berney et al., 2011a).

Successful weaning of CSCI patients from mechanical ventilation and tracheostomy requires a different approach to standard ICU rapid weaning practices due to respiratory fatigue (Blackwood et al., 2014). National recommendations provide conflicting advice. Respiratory weaning guidelines, agreed through UK expert consensus, recommend early tracheostomy placement to facilitate respiratory care (Respiratory Information for Spinal Cord Injury, 2012). However, guidance on acute SCI care recommends respiratory monitoring, frequent physiotherapy and “ideally non-invasive ventilation” for CSCI patients with injury levels C3-C5 (CRG for Spinal Cord Injury, 2016). The

lack of clear advice delays respiratory care of CSCI patients, especially in non-specialised units (Wong et al., 2012c, Atito-Narh et al., 2008). Evidence supports weaning success using progressive ventilator-free breathing protocol with a team approach (Wallbom et al., 2005, Atito-Narh et al., 2008). This protocol gradually increases the time spent off the ventilator whilst monitoring VC for signs of fatigue. This weaning process takes place over weeks rather than days and decannulation is only considered when self-ventilation is established for days rather than hours (Atito-Narh et al., 2008).

iii. **Impact on laryngeal function**

Tracheostomy and ventilation have previously been cited as factors correlating with oropharyngeal dysphagia in CSCI, although the process of disruption is not clear (Kirshblum et al., 1999, Brady et al., 2004, Seidl et al., 2010a, Shin et al., 2011, Chaw et al., 2012, Shem et al., 2012a). To ensure effective lung ventilation, patients require a tracheostomy with an inflated cuff. With no airflow through the vocal cords, the glottic closure reflex is interrupted, losing both laryngeal sensation and sub-glottic pressure, which are, essential for effective swallowing (Eibling and Gross, 1996). The loss of trans-laryngeal airflow leads to disuse atrophy of the laryngeal musculature, raising the risk of aspiration (Brown et al., 2011, Prigent et al., 2012).

The impact of tracheostomy on swallowing continues to be contentious. Early studies suggested a mechanical tethering of the larynx causing disruption to swallowing (Bonanno, 1971, Elpern et al., 1994). More recent literature in heterogeneous populations have assessed patients' swallowing with and without a tracheostomy and demonstrated no change to aspiration status or swallowing mechanics suggesting no causal relationship between tracheostomy and oropharyngeal dysphagia (Donzelli et al., 2005, Leder and Ross, 2010, Brady et al., 2009). For those requiring ventilation, the status of the tracheostomy cuff is thought to have an impact on swallowing (Ding and Logemann, 2005, McGowan et al., 2007) through disruption to the breath-swallow synchrony (Martin-Harris et al., 2005). For CSCI patients, it remains

unclear as to whether oropharyngeal dysphagia is caused by the primary injury or the respiratory interventions.

In summary, the immediate loss of respiratory function is a feature of high and low cervical injuries. Those with injuries that are incomplete or below C4 may recover some function, however careful management of secretion retention, poor cough and pneumonia is required to limit the impact of these complications on respiratory function. Often a tracheostomy is required to support mechanical ventilation. Both tracheostomy and ventilation have been identified as key risk factors for oropharyngeal dysphagia, which is an added complication. The next section will explore spinal surgery as another contributing factor for oropharyngeal dysphagia in CSCI.

2.2.5 CSCI and spinal surgery

Following a traumatic SCI, surgery is often required to fix the breaks, realign the spinal column and improve oxygenation and electrophysiology of the cord in order to minimise the neurological impact, although timing is debated (Kerwin et al., 2007). There are two parts to the surgery, firstly a discectomy, where the disc is removed, then a fusion that stabilises and strengthens the cervical segment through the use of bone graft or implants (Fengbin et al., 2013). Generally termed ‘anterior cervical spine surgery’ (ACSS), it requires access to the cervical spine through an anterior approach via the neck using traction of laryngeal and pharyngeal structures and carries a risk of damage to local areas.

Oropharyngeal dysphagia and dysphonia have been recognised as common post-operative complications following elective ACSS. The impairments are often reported as transient, with an incidence at 1 week estimated at 1% to 79% and chronic complaints ranging from 13% to 21% after 1 year (Riley et al., 2010, Bazaz et al., 2002). Increased risks of oropharyngeal dysphagia have been associated with the anterior approach, multiple surgical levels and use of instrumentation (Joaquim et al., 2014, Mendoza-Lattes et al., 2008, Leonard and Belafsky, 2011, Papavero et al., 2007).

Spinal surgery creates specific features of swallowing disruption which may explain the dysfunction and prognosis. Increased posterior pharyngeal wall thickness was identified in a retrospective review of 67 VFS studies of patients with oropharyngeal dysphagia post-ACSS (Leonard and Belafsky, 2011). This was due to insertion of metal plate to fix the spinal column. This thickness had an impact on pharyngeal transit times and epiglottic inversion although this improved over time.

Few prospective studies have reported on ACSS in traumatic SCI alone. Those within heterogeneous groups demonstrated comparatively worse outcomes (Martin et al., 1997, Zeng et al., 2013). A large retrospective study looking at the impact of surgery timing on complications (Bourassa-Moreau et al., 2013) reviewed 431 traumatic SCI cases at a single site and found that those who had surgery within 72 hours had a reduced incidence of pneumonia and pressure ulcers, both major complications. They report a further reduction in complications when surgery took place within 24 hours. There is debate as to the prioritisation of surgery over tracheostomy with concerns about site infection due to proximity of incisions. A retrospective evaluation of 71 patients admitted to an ICU with CSCI, demonstrated a low risk of infection when tracheostomy was placed after spinal surgery (Berney et al., 2008).

Posterior approach surgery has been proposed as a safer procedure with a lower incidence of oropharyngeal dysphagia. Brodke at al. (2003) undertook a randomised study allocating CSCI patients to anterior or posterior surgical approaches and reported no difference in outcomes to neurological change or pain, although those who had anterior surgery averaged 10 days to surgery compared to five for the posterior group. Smith-Hammond et al. (2004) employed both subjective and objective assessments to prospectively evaluate 83 elective patients who had undergone anterior, posterior or lumbar surgery. Oropharyngeal dysphagia was a post-operative feature identified on VFS with 50% anterior and 20% posterior surgery patients of which 31.8% demonstrated silent aspiration. They also reported poor correlation between self-reports and level of oropharyngeal dysphagia, questioning the value of subjective reports. This provides evidence that both anterior and posterior surgery to the cervical spine has a neurological impact on laryngeal function, affecting swallowing.

2.2.6 Clinical management of associated complications

Oropharyngeal dysphagia and the need for ventilation give rise to a number of secondary complications in oral hygiene, nutrition and communication (Yuen et al., 2009, MacBean et al., 2009, Thibault-Halman et al., 2011). These are rarely documented in the literature relating to CSCI patients but they contribute to quality of life and can have an impact on mortality. With lengths of stay often being prolonged, it is important to maintain good oral care, effective communication and nutrition, to minimise the impact on recovery.

i. Oral hygiene

Poor oral hygiene is associated with an increased risk of ventilator associated pneumonia (VAP) especially in long term ventilated patients (Garcia-Leoni et al., 2010). The mechanism of infection is through oropharyngeal microorganisms entering and colonising the lungs (Melsen et al., 2013). To reduce the risk of VAP and improve patient comfort, regular and effective oral hygiene is required for ventilator-dependent patients (Prendergast et al., 2013, Pileggi et al., 2011). Oral care bundles have been developed for staff in critical care to ensure implementation of multiple strategies to minimise VAP including subglottic suction, elevated patient positioning and regular oral hygiene (Department of Health, 2007, Hellyer et al., 2016). These strategies have been demonstrated as being effective for VAP and whereas subglottic suction and oral care can be implemented with CSCI patients, semi-recumbent or upright positioning may be contra-indicated. Being supine optimises vital capacity and respiratory functioning in CSCI patients (Wallbom et al., 2005) although this has been found to increase the risk of pharyngeal stasis of secretions and reflux aspiration leading to VAP (Drakulovic et al., 1999). This may explain the higher VAP incidence for ventilated SCI patients (Garcia-Leoni et al., 2010), however no alternative oral care guidelines exist for this patient group.

A further issue for many SCI patients is the experience of dry mouth or xerostomia due to the effects of medication and oxygen, which dries out the oral mucosa. This affects oral comfort as well as speech and swallowing functions (Gallagher and Naidoo, 2009). Xerostomia has been identified in the SCI

literature as a chronic issue related to reduced dental health and limited access to dentistry (Sullivan et al., 2013, Yuen et al., 2009, Pakpour et al., 2016). Saliva provides antibacterial and protective properties, and when this is reduced dentition and oral health are compromised (Mese and Matsuo, 2007). Oral dryness is often alleviated through regular fluid intake however this is not possible for those who are nil by mouth due to oropharyngeal dysphagia. Alternative solutions include the use of artificial saliva for regular mouth moisturising and limiting the use of foaming oral care products that increase dryness (McRae, 2011). Further research is needed to develop an optimal protocol for mouthcare in CSCI patients.

ii. Communication

Ventilator-dependent patients require inflated tracheostomy cuffs to ensure an effective closed ventilator system. The cuff prevents expiratory airflow through the larynx stopping phonation and speech, resulting in a reliance on non-vocal communication (Hess, 2005). The impact of no communication ability in critical care patients is recognised in the literature and linked to issues of dependency, frustration, isolation and low mood (Patak et al., 2004, Magnus and Turkington, 2006, Menzel, 1998, Radtke et al., 2011). The loss of speech leads to reduced staff interaction which increases patient isolation (Carroll, 2007). Alternative methods of communication include writing, hand and facial gestures, although these require additional facilitation to be effective (Grossbach et al., 2011, Finke et al., 2008). These options are limited for ventilated CSCI patients who have restricted upper limb movement and positioning, making gestures and face-to-face contact difficult (Hartley, 2015).

Access to high technology aids, such as eye-gaze systems, are often considered a solution. These require setting up, training and consistent positioning to achieve success, which can be a challenge for the acute CSCI patient (van Middendorp et al., 2015). Two case reports of long-term ventilated SCI patients have introduced modified aids to provide access to effective communication options that do not require movement. For one blind tetraplegic patient an electrolarynx was used with support to generate an artificial voice source (Shimizu et al., 2013) and for another a mouthstick stylus was used to access a touchscreen and generate speech (Mitate et al., 2015).

As speech is the most effective means of communication, there have been attempts at generating speech whilst ventilated. This often requires partial or full deflation of the cuff to allow airflow into the upper airway as leak speech or directing expiratory airflow using an in-line speaking valves with manipulation of the ventilator settings (Hoit et al., 2003, MacBean et al., 2009, Leder et al., 2013). These adjustments require tolerance of cuff deflation and a level of expertise to ensure there is no compromise to laryngeal and respiratory function. Cuff up phonation options have been explored recently. By utilising an alternative air source on a suction-aid tracheostomy, phonation can be achieved using an above cuff vocalisation technique (ACV), although this could not be maintained for prolonged periods (McGrath et al., 2015). The Blom Tracheostomy Tube System allows airflow above the cuff through a special valve system. Three case reports with CSCI patients reported some success with generating speech for short periods although there were issues with airflow, positioning and intelligibility (Pryor et al., 2016b).

Communication is an important function for patients, allowing interaction with staff and family and control of their environment (Radtke et al., 2011). Options for non-verbal communication are a challenge due to physical restrictions and dependence on others (Mitate et al., 2015, van Middendorp et al., 2015, Shimizu et al., 2013). Options for speech whilst ventilated either rely on leak speech via cuff deflation or experimentation with cuff-up tube manipulations (McGrath et al., 2015, Pryor et al., 2016b).

iii. Nutrition

Reliable enteral nutrition is important for survival and recovery of critical care patients, due to a rapid change in metabolism especially post-trauma (Miller et al., 2011). This can be delivered orally as food if the patient is awake and alert or using nutritionally balanced supplements via feeding tubes if level of consciousness is reduced (McClave et al., 2014). For CSCI patients, the process of spinal shock during the acute phase may affect the digestive system, known as paralytic ileus. This affects the transmission of food through the gut, or gastroparesis, delayed emptying, resulting in gastric distension, vomiting and the risk of reflux aspiration (Taneja et al., 2013). Routine management of

paralytic ileus recommends that SCI patients are kept nil by mouth until gut function returns, which may take days or weeks. A nasogastric tube is used to drain gastric contents and limit distension with medication to assist recovery of function (Denton and McKinlay, 2009). During this time feeding is withheld as early enteral feeding may prolong gastric dysfunction and distension, compromising respiratory function by splinting the diaphragm (Karlsson, 2006).

The timing of enteral feeding and risk of under-feeding are key issues in the nutritional management of acute SCI. Delays in commencing enteral feeding lead to a higher incidence of malnutrition in SCI patients (Wong et al., 2012a) that may compromise recovery. To determine the safety of early feeding a prospective randomised clinical study allocated 17 SCI patients to either early (within 72 hours) or late (after 120 hours) enteral feeding (Dvorak et al., 2004). Although the early group achieved energy goals sooner, they had a greater duration of ventilation and same rate of pneumonia in both groups, demonstrating no overall difference. A retrospective review of enteral feeding times in SCI patients in ICU found that enteral feeding could be safely commenced within 2 days if high gastric aspirates were monitored (Rowan et al., 2004). Both these studies have small samples limiting generalisation, however they attempt to document the evidence to support earlier enteral feeding and limit the risk of under-feeding.

Early studies on biochemical markers in SCI patients identified a number of metabolic changes in the acute period including low levels of serum and pre-albumin which could be suggestive of poor oral intake and malnutrition (Barboriak et al., 1983, Laven et al., 1989). A systematic review of acute SCI nutritional management identified a high incidence of metabolic abnormalities, including lowered albumin, with a recommendation to limit nutritional deficiencies through enteral feeding (Thibault-Halman et al., 2011). One retrospective study in acute CSCI patients suggested that early signs of lowered serum albumin and pre-albumin levels were indicative of higher mortality after significant variations in levels between those that died (n=19) compared to survivors (n=109) although it is unclear whether malnutrition or trauma was the cause (Chen et al., 2014). Recently the use of serum albumin levels to determine nutritional status has been challenged due to its wider sensitivity to

non-dietary factors such as infection, inflammation, trauma, surgery and cancer (Bharadwaj et al., 2016). Nutritional assessments are recommended to ascertain malnutrition in conjunction with biochemical results.

The routine use of nutrition screening tools have been promoted through national guidance to detect malnutrition risks and support early interventions (National Collaborating Centre for Acute Care, 2006). The Malnutrition Universal Screening Tool (MUST) (Elia, 2003) is a five-step screening tool using weight, height, weight loss and severity of disease to estimate risk of malnutrition to plan management. This tool is now widely used across the UK in different settings (British Association of Parenteral and Enteral Nutrition, 2003). Despite the wide use of the MUST, 44.3% of SCI patients were found to be at risk of malnutrition on admission to a UK spinal unit (Wong et al., 2012a). High cervical injury patients showed greater risk than lower cervical injuries (60.7% vs 34.5%) and ventilated patients more than non-ventilated (56.3% vs 38.7%). This led to the development of a SCI-specific screening tool, the Spinal Nutrition Screening Tool (SNST), to better identify risk to nutrition (Wong et al., 2012b). The SNST uses 8 components that consider associated medical aspects, which make it more sensitive than the MUST. The SNST includes level of injury, skin condition, appetite and ability to eat although and whilst oropharyngeal dysphagia is not a considered, being nil by mouth and ventilated would identify high-risk patients. The use of screening tool is still not routine (Wong et al., 2012b) which may make nutritional decisions inconsistent especially when SCI patients transfer across form non-specialised to specialised units (Wong et al., 2012a).

The presence of oropharyngeal dysphagia additionally impacts on SCI nutrition, recovery and rehabilitation. Dionyssiotis (2012) acknowledged this factor, recommending early enteral feeding especially for more complex CSCI. National nutritional guidance (National Collaborating Centre for Acute Care, 2006) advocates the use of nasogastric tubes for a period of 4-6 weeks for acute patients with evidence of oropharyngeal dysphagia, after which time longer term feeding options, such as percutaneous endoscopic gastrostomy (PEG) need to be considered. PEG has been supported as an early option for trauma patients (Dwyer et al., 2002), favouring over surgically inserted tubes

with lower complication rates (7.4% vs 30.2%) due to need for only local rather than general anaesthetic and puncture rather than incision technique. Three case studies of CSCI patients with PEG suggested that clinical signs were subtle following tube dislodgement making detection a challenge leading to mortality of two patients (Hess and Foo, 2010). These reports have led to resistance in PEG placement and a preference to push oral intake despite the unseen risks of oropharyngeal dysphagia (Mullender et al., 2014). Early screening of oropharyngeal dysphagia risks helps to plan effective and safe nutritional support if required.

2.2.7 Risks to mortality in CSCI

SCI compromises a number of body systems, with CSCI affecting both cardiac and respiratory systems, raising the risk of mortality. In the early 1990's, prior to the advancement of paramedic trauma skills and ICU technology, the one-year survival rate for ventilator-dependent SCI patients was reported as 25.4%, with just under half of these patients dying from a respiratory cause, and pneumonia developing in 63% of acute high cervical injuries (Jackson and Groomes, 1994, DeVivo and Ivie, 1995). Increased access to high-level training and technology has provided staff with skills to intubate, ventilate and monitor patients at site of injury until admission to ICU where trauma care continues (Como et al., 2005). As the numbers of CSCI survivors increased, retrospective studies have attempted to identify the risk factors affecting early mortality in order to minimize their impact (DeVivo et al., 1993, Devivo, 2012, DeVivo and Ivie, 1995). Overall, mortality is considered to be three times higher than the normal population (van den Berg et al., 2010).

2.2.7.1. Risk factors

Age, gender, level and severity of injury have been highlighted as risk factors following traumatic and non-traumatic SCI (Prusmack et al., 2006, Hasler et al., 2012, Martin et al., 2011). A systematic review of worldwide reported survival after SCI found that secondary complications rather than injury were the leading cause of death, with respiratory failure being a key factor (van den Berg et al., 2010). A UK cohort study of CSCI admissions identified increased odds ratios

(OR) for age over 35 years peaking at age 65 years and over (OR 1.72; 95% CI, 1.44–2.06), with reduced risk for females (OR, 0.59; 95% CI, 0.53–0.65) (Hasler et al., 2012). To explore these factors and their contribution to mortality, the following sections will review the literature on age, gender and reported causes of death following CSCI.

i. Age

The demographics of those with SCI has been gradually changing from an average age of 28 years to over 37 years old, in line with the general ageing population (Devivo, 2012). A number of retrospective studies have reported higher mortality rates in their study cohorts as age increases, however methodology and populations samples differ, making generalisations a challenge. The cut off point for the impact of age varies, Varma et al. (2010) reviewed early mortality in all ages of traumatic SCI patients admitted to multiple acute units in USA over 10 years, concluding that those aged over 20 years with comorbidities demonstrated significant mortality.

Two studies reported a significant increase in mortality for those aged 45 years and over. A UK retrospective review of outcomes over 25 years for 189 ventilated patients identified a three times increase in death in those over 46 years old and dependent on mechanical ventilation (Watt et al., 2011). A smaller retrospective study of 147 SCI patients at a single unit in USA reported a five times increased risk to mortality for those aged 45 years or older at injury (Rabadi et al., 2013). Although increasing age appears to have an impact on mortality in SCI it is important to explore the added impact of the injury itself.

Prusmack et al. (2006) compared outcomes for SCI patients below and above the age of 60 years. Those over 60 years had a higher level of cervical injuries due to falls and only a 50% survival at 1 year compared to 91% in those under 60 years. Pneumonia was the leading cause of mortality. An analysis of mortality factors in a cohort of SCI patients aged 60 years and over, identified level of injury over C4 as increasing the risk of mortality by seven times and complete injury increasing risk by five times (Daneshvar et al., 2013). Both these contribute to respiratory failure which is the leading cause of death. Similarly, pneumonia was identified as a leading cause of mortality in a cohort of 244 CSCI over the age of 70 years, linked to level and severity of injury

(Martin et al., 2011). Older age appears to affect the natural process of spinal degeneration and increase the incidence of other health conditions that negatively influence the recovery process (Liang et al., 2001).

Links have been made between age and risk of oropharyngeal dysphagia in CSCI. Age over 50 years was reported to be a significant predictor of oropharyngeal dysphagia in retrospective studies (Shem et al., 2012a, Shin et al., 2011). Other studies report age as a factor when linked to other factors, such as level and severity of injury (Shem et al., 2005, Seidl et al., 2010a, Kirshblum et al., 1999). In contrast, a number of studies found no correlation with age and level of oropharyngeal dysphagia despite populations with extensive age ranges (Brady et al., 2004, Wolf and Meiners, 2003, Abel et al., 2004). It is still unclear as to whether age increases the risk of oropharyngeal dysphagia following CSCI.

ii. Gender

Male gender has been identified as an increased risk factor for mortality in SCI (Hasler et al., 2012, Varma et al., 2010, Chamberlain et al., 2015). This may be influence by the higher ratio of men with traumatic SCI compared to women, particularly in the under 30 years age group, (Nussbaum, 2004, Lau et al., 2014). There are variations to reported male-female ratios in studies of between 5.5:1 to 1.2:1 (van den Berg et al., 2010) with an associated increase in injury severity for men (Varma et al., 2010). One study reports higher female mortalities however this is due to suicide post-SCI rather than the SCI itself (Hagen et al., 2010). Gender is a feature of SCI that may have an impact on mortality, when linked with other factors.

No links has been reported between gender and oropharyngeal dysphagia post-CSCI (Kirshblum et al., 1999, Shem et al., 2011, Bradley et al., 2011). In contrast, studies on oropharyngeal dysphagia following elective cervical spine surgery have suggested strong gender differences with complications occurring more in females (Yue et al., 2005, Riley et al., 2010, Anderson and Arnold, 2013, Papavero et al., 2007). No explanation has been provided for this and Joaquim et al. (2014) suggest that as gender is not preventable, other intra-operative strategies should be employed to reduce risk. The caseloads for

elective and trauma patients do differ, but the risks of surgery for SCI patients need to be considered regardless of gender.

iii. Cause of death

The factors of age and gender are relevant in SCI but cannot be adjusted following injury, therefore understanding the causes of mortality is important to plan preventative clinical interventions. Respiratory causes are often reported as the main reason for death (van den Berg et al., 2010, Daneshvar et al., 2013) with pneumonia described as a key presenting feature. A recent systematic review of SCI mortality identified an increased risk of mortality with greater age, higher lesions and complete injuries with pneumonia identified as a leading cause of death (Chamberlain et al., 2015). In CSCI, pneumonia has been linked to respiratory insufficiency due to lung atelectasis, preventing adequate secretion clearance resulting in infection (Fishburn et al., 1990, Kang et al., 2006).

An improvement to respiratory management was thought to help to reduce this negative consequence by keeping lungs inflated through ventilation via tracheostomy. Despite this change to practice, a comparison of survival trends over 30 years (Shavelle et al., 2006) found that pneumonia remained a leading cause of death for ventilator-dependent patients. Recent studies continue to report pneumonia as a cause for in-hospital mortality of cervical level injuries (Rabadi et al., 2013, Grossman et al., 2012, Aarabi et al., 2012, Wilson et al., 2012). In contrast, a single site retrospective study of 244 CSCI cases over 5 years found no correlation between pneumonia and mortality instead death was linked to level and severity of injury and age (Martin et al., 2011). This variation may have been due to the exclusion of participants with worsening respiratory condition who did not transfer to their spinal unit. For this reason, it is valuable to review patients in both specialised and non-specialised units to better identify the contributing factors without bias.

Retrospective studies that select mortality as an outcome measure do not always provide specific details of clinical management. To identify the causes of early mortality in 1163 CSCI patients admitted to a single hospital were reviewed (Shao et al., 2011). Outcome measures included timings of

tracheostomy placement, surgery and serum albumin levels as a measure of nutrition. A mortality rate of 9.4% was identified within 30 days of admission, with tracheostomy and malnutrition as significant associations. Overall, CSCI patients with injuries at levels C1-C5 had a higher risk of mortality alongside an ASIA grade A, however those who had surgery were less likely to die early, suggesting protective factors. The authors identify a lack of standardised care resulting in variations to timing of tracheostomy and surgery, which may have had an impact on mortality. Other studies report lower mortality related to level and severity of injury, and suggest a link to specialised clinical care in a trauma or spinal centre which minimises the impact of these factors (Varma et al., 2010, Chamberlain et al., 2015). For those who remain in non-specialised unit, the level and severity of injury are likely to contribute more to the risk of mortality.

2.3. Conclusion

The mechanism of CSCI causes multi-system impairments that demand immediate clinical interventions, such as tracheostomy, ventilation and surgery, to preserve life and minimise the impact of the injury. Level and severity of injury alongside increased age and male gender have been identified as predictors for mortality with respiratory infections and pneumonia as the leading cause of mortality. Clinical management has focussed on improving respiratory care to prevent these complications and the secondary effects on nutrition.

Oropharyngeal dysphagia is a significant contributory factor in respiratory dysfunction and is linked to multiple factors, such as tracheostomy, ventilation, surgery and level of injury. With many of these interventions coinciding, it is difficult to identify a single factor causing disruption to swallowing. Presentation is often subtle with reports of predominantly pharyngeal dysfunction and silent aspiration. Together with the loss of respiratory function and cough this raises the risk of secretion retention and chest infections. Prevention relies on early identification through screening, however no clear guidance exists. Consideration has also been given to the secondary impacts of oropharyngeal dysphagia and ventilation, namely oral hygiene and communication problems. As these do not have an impact on mortality they are rarely reported in this

patient group, however, they contribute to the experience of quality of life, especially in the acute phase of care.

The overall aim of this study was to understand variations in the management of oropharyngeal dysphagia for CSCI patients and develop a swallow screening tool to improve the identification of risk for oropharyngeal dysphagia in CSCI patients. The initial study investigated current practices by critical care staff in specialised and non-specialised units for the clinical management of oropharyngeal dysphagia and associated impairments. The next study investigated the lived experience of acute care by CSCI patients and their families through semi-structured interviews. This data would ensure relevance of future best practice recommendations to the current care pathway. A Delphi process was used to gain international clinical expert consensus on risk factors for oropharyngeal dysphagia, best practice recommendations for oropharyngeal dysphagia management, in the absence of empirical studies. The areas of risk were grouped to form the components of a swallow risk screening tool. Usability of the tool was evaluated through a pragmatic observational feasibility study at two trauma sites. Changes in staff clinical-decision making, pre- and post- tool demonstrated variability in tool utility. Further research at multiple sites would help to evaluate the impact of the tool in varied settings and identify clinical outcome measures.

3. Study 1: A UK survey of multi-professional staff on clinical practice with acute CSCI patients

3.1. Introduction

Appropriate and consistent care is essential for all SCI patients, especially those with CSCI and complex impairments, resulting in a high level of physical dependency (National Institute for Health and Care Excellence, 2016). Protocols to manage these complexities are developed to ensure staff deliver standardised care to all patients. Specialised SIUs are considered as the dedicated sites for SCI care, however with improved survival rates and increasing cervical level injuries (McCaughey et al., 2016, Strauss et al., 2006), demand has surpassed bed capacity in SIUs in England (Spinal Injuries Association, 2015). As a result, many SCI patients remain in non-specialised units for extended periods of time before SIU transfer for on-going rehabilitation. There are few studies investigating the impact of non-specialised units on acute SCI management. An early Canadian study compared outcomes for patients before and after their introduction of a specialised spinal unit (Tator et al., 1995). The authors report reduced mortality and length of stay for all SCI patients when managed in a multi-disciplinary specialised spinal unit. This was shown to be of particular benefit for those with CSCI when respiratory complications were managed early. More recently, an Australian study (New et al., 2011a) looked at the impact on patients admitted to different types of units and identified a lack of uniform standards affecting outcomes, with a recommendation for increasing expertise of staff at non-specialised units. A systematic review of the impact of acute care in specialised units with regards to length of stay, complications and mortality (Parent et al., 2011) identified 15 studies with reported outcomes for a cohort of at least 10 patients. For patients who were transferred to a spinal unit promptly after injury, they reported reduced length of stay, fewer complications and greater neurological recovery, supported by staff with clinical expertise. Although the evidence was generally weak two recommendations were made by the authors; firstly, to facilitate early transfer to a SIU and secondly, to engage with multi-disciplinary staff to reduce the severity and rate of complications and overall mortality.

Across UK and Ireland there are 12 spinal units, with eight located in England, under the centralised NHS system. The total number of beds in these units the system is under pressure and unable to meet the demands particularly of those with acute CSCI. A recent report by the Spinal Injuries Association (2015) reported the total number of SIU beds in England was 375, with 28 allocated to ventilated patients. As referral numbers exceed the capacity this leads to significant delays in transfer of patients to SIUs, leading to an increased report of complications and reduced outcomes. Whilst SIU bed numbers are unlikely to change, this study sought to understand clinical practices across specialised and non-specialised units.

An estimated 30-44% incidence of oropharyngeal dysphagia (Shem et al., 2012a, Chaw et al., 2012) adds to the complexity of managing CSCI patients, with an increased need for respiratory support (Shem et al., 2012a). This demands specialist care in a specialised unit (Wong et al., 2012c), however delays to transfer increase the risk of added complications such as pneumonia (Spinal Injuries Association, 2015) and poorer outcomes (Failli et al., 2012, Kopp et al., 2017).

3.2. Background

To provide context to the study, existing clinical guidance for critical care units will be detailed with consideration for the CSCI patient requiring tracheostomy and ventilation care. This is followed by a review of existing specific recommendations for acute CSCI management and the role of the multi-disciplinary team in delivering care in ICU.

3.2.1 Clinical guidance for critical care

Critical care services deliver specialist care to patients with failing organ systems, such as respiratory, cardiac or neurological, in order to prevent deterioration or death (Department of Health, 2000). CSCI patients experience dysfunction of all these systems, thereby requiring the highest level of critical care services, described as Level 3 (Department of Health, 2000). As cardiovascular and neurological functions stabilise, it is possible for CSCI patients to step down to Level 2 facilities, with on-going monitoring of other

dysfunctions to reduce risk of mortality. However, long-term ventilation required by CSCI patients often demands increased staff support and prolonged ICU admission due to the risk of instability.

In 2007, the National Institute for Health and Care Excellence (NICE) published guidance on the care of the deteriorating patient, following concern about variability of care (2007). Although it did not specify SCI patients, it made recommendations for the routine monitoring of physiological features for all critically ill patients in order to anticipate deteriorating functions (2007). Following this, guidance on the rehabilitation of critical care patients was established (2009) to help transition patients out of critical care more effectively. This emphasised the importance of early assessment of physical and non-physical impairments, specifying a range of risk factors including respiratory problems, swallowing difficulties and difficulties speaking. According to NICE (2009), a comprehensive clinical assessment of these risk factors would help to determine short-term and medium-term goals and develop a structured, individualised rehabilitation programme.

Setting core standards for intensive care units, the Intensive Care Society (ICS) made recommendations for minimum staffing requirements in order to provide a safe environment in critical care (2013). Clinical pathways were generalised for all patients rather than being condition-specific. As the demands on intensive care increased, ICS reviewed and expanded their guidance to provide a comprehensive set of standards, entitled Guidelines for the Provision of Intensive Care Services (GPICS) (2015) to include structure, processes and activity in critical care, against which all units are expected to audit their activity. GPICS (2015) specified the need for tracheostomy patients to be assessed for swallowing and communication needs when the weaning process is considered, in line with RCSLT recommendations (2014). GPICS (2015) also issued guidance specific to SCI care, recommending the use of protocols to facilitate referral and early transfer to SIU, linking with national guidance (National Spinal Cord Injury Strategy Board, 2012), however this guidance does not make allowances for managing extended SCI admissions.

Following a review of trauma care in 2010, the need for dedicated SCI care was highlighted with the expectation that early transfer would ensure specialist clinical interventions (NHS Clinical Advisory Group, 2010). The newly developed National SCI Strategy Board (2011) found that delays to SIU transfer correlated with an increased incidence of patient complications and length of stay. To ensure a consistent approach to care, they developed guidance for staff in non-specialised units (National Spinal Cord Injury Strategy Board, 2012) based on expert consensus. The future aim was to develop joint protocols between MTCs and SIUs to encompass many aspects of SCI care, including ventilation and weaning. However, no specific focus was made to address issues of oropharyngeal dysphagia, nutrition, oral care or communication. A recent update of the national guidance for SCI re-iterated the need for input from specialist MDT in order to avoid complications, although no reference was made to oropharyngeal dysphagia and associated impairments (CRG for Spinal Cord Injury, 2016). In the absence of agreed guidance, it is important to understand the clinical management of long-staying CSCI patients with oropharyngeal dysphagia who remain in non-specialised units.

3.2.2 Multi-disciplinary team working in critical care

The premise for multi-disciplinary team working is that each professional brings their own specialist skill to help problem solve a complex clinical issue (NHS England, 2014). This is especially valuable and important when patients have several impairments affecting multiple systems to ensure that every issue is considered and managed in an optimal way. The link between multi-disciplinary input in critical care and improved outcomes was recognised in early studies (Wheelan et al., 2003, Reader et al., 2009) and subsequently supported by a number of national guidance documents. Recommendations on rehabilitation after critical illness (2009) directs responsibility to the whole clinical team without assigning roles to specific professionals. Recent professional guidelines (Intensive Care Society, 2015) provided more specific recommendations on the requirements of a multi-professional team, to include '…Critical Care physicians, Critical Care nurses, physiotherapists, pharmacists, dietitians, and speech and language therapists with specialist expertise and experience…using agreed protocols based on the best evidence available'. These were based on expert consensus with recommendations made for the

need for further research to establish evidence. The next section will review some of the existing evidence for MDT practices for tracheostomy, CSCI and oropharyngeal dysphagia.

3.2.3 MDT and tracheostomy care

The need for respiratory support via a tracheostomy is a common cause for ICU admission due to the risk of an altered airway and the need for specialist care, as required by CSCI patients. Oropharyngeal dysphagia has been linked with the presence of tracheostomy with negative consequences for patients (Hales et al., 2008, Ding and Logemann, 2005). A multi-disciplinary approach to tracheostomy management has been supported by recent reports, in order to reduce risks and achieve better outcomes (UK National Tracheostomy Safety Project, 2013, National Confidential Enquiry into Patient Outcomes and Death, 2014). These reports have identified a lack of training and competency development amongst professionals caring for those with tracheostomies.

A number of studies have reported on the clinical benefits of an MDT approach to tracheostomy care, however, methodological challenges to data analysis of predominantly observational studies together with small patient numbers and heterogeneous caseloads have limited generalisability. A systematic review of the impact of tracheostomy teams on patient outcomes (Speed and Harding, 2013) identified seven papers and reported low quality evidence to support the benefits of teams. A reduction in length of stay and complications were demonstrated in studies with newly developed multi-professional team involvement (Norwood et al., 2004, Tobin and Santamaria, 2008). A cross-discipline approach was enhanced when additional staff education and care bundle were included (Cetto et al., 2011). Although improved co-ordination of decision-making for complex patients is supported by these studies, the variations in team structures and procedures has made it difficult to implement this approach (Wheelan et al., 2003, Grol et al., 2007).

Identifying what mechanisms help tracheostomy teams achieve successful outcomes provides a potential framework for future development. Mitchell et al. (2013) undertook a qualitative study interviewing team members at a large unit

individually and through a focus group. Team members reported the need to develop protocols in order to streamline processes with a collaborative approach reducing professional variations and generating more effective and clinically relevant decisions. According to Reader (2009) autocratic decisions were often made when dealing with more complex patients, however when a protocol was used with clear treatment goals and roles, this resulted in better communication and coordination between professionals, with benefits for patients. There are few protocols used for SCI patients, often these are for the management of skin pressure areas and bowel care and are implemented within specialised SIUs only. The next section will review multi-disciplinary care for CSCI patient management, with particular reference to oropharyngeal dysphagia.

3.2.4 MDT management of CSCI and oropharyngeal dysphagia

The multiple impairments of CSCI demand management by multiple professionals and in the case of oropharyngeal dysphagia, this has a direct impact on respiratory function (Chaw et al., 2012), nutrition (Dionyssiotis, 2012) and oral hygiene (Sullivan et al., 2013). The focus for multi-disciplinary teams is to reduce the risk of complications through collaborative working. A number of small studies have demonstrated the value of respiratory therapists working alongside SLT to provide earlier interventions preventing respiratory complications (Shem et al., 2012a, Wong et al., 2012c, Chaw et al., 2012). However, these have taken placed in a specialised SIU setting, with existing staff expertise in SCI care.

The clinical management of respiratory impairments has posed challenges for staff in specialised and non-specialised units that benefit from multi-disciplinary team working. A small case series of four dysphagic SCI patients identified their varied needs compared to their usual caseload so that existing decannulation criteria had to be modified (Ross and White, 2003). Through joint clinical working safe decannulation was achieved. The value of interdisciplinary team working was also demonstrated in a matched-pairs design study comparing the outcomes of 34 SCI tracheostomy patients pre- and post-team involvement within a large hospital (Cameron et al., 2009). The team carried out twice-

weekly rounds with SLT, PT, physician and nurse input achieving earlier speaking and fewer adverse events. Early intervention within the first few weeks post-injury was seen as crucial to identify risks, prevent complications and achieve successful outcomes. With this model in mind, Rozeboom et al. (2012) set up a team for early preventative intervention of acute SCI patients in their ICU. Although there were challenges to changing practice, these were overcome by developing unified documentation and care plans for all professionals to follow.

With supporting evidence of the benefits of a MDT approach, there remains little data on the optimal team structure and pathway required to effectively manage acute CSI patients with oropharyngeal dysphagia in non-specialised units. The current study seeks to clarify the clinical practices of multi-disciplinary staff in specialised and non-specialised settings in UK in order to identify gaps and variations, as this remains unknown.

3.2.5 Study aims

To identify variations in practices and make clinical recommendations for improved care, this study aimed to examine clinical decision-making in the management of acute CSCI patients by multi-professionals based in specialised and non-specialised units. Specialised units were those that deliver clinical services to patients with a specific disorder, such as spinal cord injury, neurological or cardiothoracic impairments, this includes Spinal Injury Units (SIU) and Specialist Hospitals (SPH). Non-specialised units are those that deliver care to a heterogeneous population, this includes major trauma cantres (MTC), district general hospitals (DGH) and teaching hospitals (TCH).
The research questions were:

i. Do non-specialised and specialised units differ in the clinical management of oropharyngeal dysphagia and associated impairments of respiratory function, nutrition, communication and oral care in CSCI patients?

ii. Are members of the multi-disciplinary team consistent in clinical management of oropharyngeal dysphagia and associated impairments?

The results of this survey would provide an insight into current clinical practice in the approach to oropharyngeal dysphagia management across units to identify consistent practices and areas requiring further development.

3.3. Methods

3.3.1 Survey design and development

No previous surveys had been developed to investigate UK multi-professional practices in the management of oropharyngeal dysphagia in acute CSCI. A new survey was created to include topics derived from existing national guidance (Respiratory Information for Spinal Cord Injury, 2012) and literature on identification and management of oropharyngeal dysphagia in CSCI with consideration of associated complications (Shem et al., 2012a, Brady et al., 2004, Wolf and Meiners, 2003).

Guidance on survey design was followed (Dillman et al., 2009) with reference to minimising bias and using multiple choice and free text options to improve response rates. The survey was created and distributed online using SurveyMonkey (www.surveymonkey.net), a familiar online survey system. A steering group was set up with a senior nurse, doctor, PT, SLT and dietitian with acute SCI expertise based at a specialised unit known to the lead researcher. The group provided feedback on the order of questions, use of terminology and clarity of questions used in the survey to ensure suitability for multidisciplinary respondents. Comments from the group were received through face-to-face meetings and email responses.

The first version of the survey was planned to be profession specific using skip logic, to ensure navigation to relevant questions based on previous responses. Feedback from the steering group supported merging questions into a single survey to allow comparison of responses for the same questions by all multidisciplinary respondents. Additional comments were received suggesting further response options and removal of less familiar terms (Appendix 4), for example, replace ‘ventilator-free breathing’ with ‘spontaneous breathing trials’. In response to comments, a single questionnaire was developed with 33 questions and amended response options. A second round of feedback targeted the clarity of terminology for the different disciplines, adding ‘don’t

know' options for certain questions and the use of skip logic for questions where the answer was 'no'.

The final survey had a total of 35 questions (Appendix 5). The front page listed study details with consent implied through commencement of the survey. An exclusion question eliminated participants not working in units admitting SCI patients. The survey was structured as follows: hospital type (section 1); demographic information (section 2); ventilator and tracheostomy weaning (section 3); nutritional decisions (section 4); oropharyngeal dysphagia management (section 5); mouthcare (section 6) and communication support (section 7). All questions had pre-defined responses and either single or multiple selections were required depending on the question. At the end respondents were able to leave comments in a free-text box with contact details for those interested in future involvement in the study.

3.3.2 Study ethics

Ethical approval was granted by NRES Committee London-Stanmore REC (Ref: 14/LO/1209) and NHS R&D approvals (IRAS ID: 129588) to disseminate the survey to NHS staff (Appendix 1).

3.3.3 Participants

The target audience were doctors, nurses, PTs, SLTs and dietitians working in critical care units based in major trauma centres (MTC), district general hospitals (DGH), teaching hospitals (TCH), specialist hospitals (SPH) and spinal injury units (SIU) in the UK that admit acute CSCI patients. Respondents were excluded if they did not hold one of the listed professional roles, worked outside the UK or did not work with SCI patients.

A sample size of 207 achieves 95% power to detect a medium effect size of 0.30 between the hospital types (MTC, DGH, TCH, SPH, SIU) using a 4 (5-1) degrees of freedom Chi-Square Test with a significance level (alpha) of 0.05 (Cohen, 1988). This would also allow for comparisons between the 5 professional groups, namely doctors, nurses, PTs, speech and language therapists (SLTs) and dietitians. Equal representation of professionals were unlikely to be achieved due to variations in staffing levels within units and the

use of teams to provide care across 24 hour shifts (Critical Care Network-National Nurse Leads, 2016).

3.3.4 Survey distribution

To overcome challenges to recruitment, snowball sampling was used so that study participants recruited other study participants from the five professional groups (Atkinson and Flint, 2001). An email invitation, participant information sheet (Appendix 6) and survey web link was distributed to staff through professional bodies and clinical networks using a variety of established communication methods including social networking and e-newsletters (Table 3.1). Paper flyers were used for additional promotion of the survey at relevant conferences and meetings. The survey opened to responses in August 2014 and closed in January 2015.

Table 3.1 Distribution of survey link to professional bodies and networks

	Group	**Method of distribution**
Professional bodies:	Intensive Care Society (www.ics.ac.uk)	Twitter, Facebook, Website, e-newsletter
	Royal College of Speech and Language Therapists (www.rcslt.org.uk)	Twitter, Facebook, research newsletter
	British Dietetic Association critical care group	Email
	British Association of Critical Care Nurses (www.baccn.org)	Website link
	Special Interest Group of Physiotherapists in critical care	Email
Professional SCI networks:	Multi-disciplinary Association of Spinal Cord Injury Professionals (MASCIP)	Email, Facebook
	British Association of Spinal Cord Injury Specialists (BASCIS)	Email
	Respiratory Information for Spinal Cord Injury (RISCI) membership and conference	Email, flyer
	Guttman multi-disciplinary representatives from spinal units - membership and conference	Email, flyer
	Members of 19 Critical Care Networks in England (accessed from www.oaawebcast.info)	Email

Respondents were anonymous but were offered the opportunity for future involvement in the study by submitting their email details at the end of the survey. Participation was voluntary with the option to leave the survey at any point. No rewards or incentives were offered for completion of the survey.

3.3.5 Data analysis

The final survey consisted of single and multiple response options, together with free text (Table 3.2). This produced both quantitative and qualitative results used to evaluate variations between unit types and professional groups. Following survey completion, data was downloaded from SurveyMonkey to SPSS Version 22 (SPSS, Chicago, IL, USA) to generate descriptive data and test for statistical significance. This included the number and percentage of participants per question; the number and percentage of responses per question for multiple options; number and percentages per hospital type and per professional group.

To identify variations in the care delivered to CSCI patients responses were grouped into those from specialised and non-specialised hospitals. Responses from SIU and SPH were grouped as specialised hospitals, whilst MTC, DGH and TCH responses were grouped as non-specialised hospitals. These were the key areas for comparison per question followed by responses per professional group. Tests of association used were Chi-Square test of independence or Fisher's Exact Test if expected counts were <5. Statistical significance was set at $p<0.05$.

A separate analysis was conducted, of the qualitative data generated through free-text comments at the end of the survey. These were uploaded directly to NVivo 10 (QSR International) and analysed thematically through a six step process according to Braun and Clarke (2006). This involves a process of familiarisation with the data, generation of initial codes, developing potential themes, refinement of the themes through data review, defining and naming the themes and finally, reporting the themes that represent the data.

The results of interest, comparing specialised and non-specialised units, and professional groups will be reported next. Where percentage results are

compared, results from non-specialised units will be reported first followed by specialised units. Further survey data for hospital types and professional groups are sited in Appendices 8 and 9.

Table 3.2 Final survey with response types for analysis

Section 1 Hospital and unit details:	Single response (SR), Multiple response (MR), Free Text (FT)
1. What type of hospital do you work in?	SR
2. How many beds does the hospital have?	SR
3. What is the main hospital ICU that you work in?	SR
4. Does your intensive care unit have established links with a ..	SR
5.How many level 3 beds does your intensive care unit have?	SR
6.Does your intensive care unit admit patients with spinal cord injury?	SR (exclusion question)
7. Does your unit have specific care pathways for managing:	MR
8.Which Spinal Outreach Team does your unit have access to?	MR
Section 2: Demographic details	
9. What profession are you?	SR
10. What grade are you?/11.What banding are you?	SR (skip logic)
12. What is your clinical specialism?	MR
Section 3: Ventilator and tracheostomy weaning	
13. Who is regularly involved in your tracheostomy team?	MR
14. Who determines the weaning programme of ventilated spinal cord injured patients?	MR
15. What protocol does the team use for ventilator weaning of patients with cervical spinal cord injury?	SR
16. What is the first priority when planning a ventilator weaning programme?	MR
17. As part of the ventilator weaning process do you use:	MR
18. What do you consider is the impact of an inflated tracheostomy cuff?	MR
19. Do you routinely block off a tracheostomy before decannulation?	SR
Section 4: Feeding	
20. What criteria does your unit use for commencing non-oral feeding in a spinal cord injured patient?	MR
21. What will determine the change from a nasogastric tube to a gastrostomy feeding tube?	MR
22. When do you consider a cervical spinal cord injured patient is ready to start eating?	MR
Section 5: Swallowing	
23. Who screens for swallowing problems on the intensive care unit?	MR
24. How are swallowing problems determined on ICU?	MR
25. What clinical signs do you consider are evidence of swallowing problems in patients with a cervical spinal cord injury?	MR
26. What are the criteria for referring to Speech and Language Therapy?	MR
27. What swallowing assessment/s does the Speech & Language Therapist routinely use for patients on ICU?	MR
28. Do you consider it safe to allow a patient to eat and drink whilst they have the cuff inflated on their tracheostomy tube?	SR
Section 6: Mouthcare	
29. Are you involved in the delivery of mouthcare? If yes → 31	SR (skip logic)
30. Who is responsible for oral hygiene on your unit?	SR
31. How is the frequency of oral care determined?	SR +FT
32. Do you advise on the following aspects of oral hygiene?	MR
Section 7: Communication	
33. How do you support patients with a tracheostomy and cervical spinal cord injury who cannot speak in ICU?	MR
34. Is cuff deflation considered a communication option for ventilator dependent patients?	SR
35. Do you use in-line speaking valves with ventilator dependent patients?	MR
Section 8: Comments	
36. Do you have any other comments you would like to add about the clinical management of cervical spinal cord injured patients?	FT (optional)
37. If you would like to be involved in a future aspect of the study to develop a screening tool, please add your email address:	FT (optional)

3.4. Results

3.4.1 Survey responses

A total of 221 survey responses were received, two respondents were excluded as they were based at overseas units, leaving 219 for analysis. Thirty-one participants responded that their unit did not admit acute SCI at the exclusion question (no. 6), which ended their survey participation. There was a 36% loss of responses by the end of the survey. It was not possible to calculate a response rate as the actual number of staff working with acute SCI patients was unknown. For this reason, snowball sampling was used to engage as many suitable participants as possible, however it is possible that not all participated. Responses to the survey were analysed by question topic, reporting the number of respondents (n) per question, and the number of responses for questions permitting multiple answers.

3.4.2 Respondent demographics

Five hospital types were represented in the results with the largest group of respondents based in MTCs (40.2%), followed by DGHs (26.9%), TCHs (14.2%), SIUs (13.2%) and SPHs (5.5%). Staff from non-specialised units (MTC, DGH and TCH) totalled 81.3% of respondents. Respondents came from 87 hospitals across the UK (Appendix 7). Most respondents from non-specialised units were based in hospitals with over 500 beds (75.8%), and over 10 level 3 beds, whereas more staff in specialised units (SPH and SIU) were based in hospitals with less than 500 beds (58.5%) with less than 10 level 3 beds (63.2%) (Table 3.3).

Non-specialised units had representation of all five professional groups, namely doctors (35.0%), nurses (33.6%), PT (13.1%), SLT (12.4%) and dietitians (5.8%) whereas specialised units had no dietetic representation (Table 3.4). In terms of staff grading, the majority of doctors were consultants (96.2%) and the remainder were specialist registrars. Half of all nurses and AHP respondents (50.9%) were band 7 senior clinicians, a quarter were band 6 clinical specialists (25.9%) and a fifth were advanced specialists at band 8 (21.4%). Only two nurses were at basic grade band 5 (Table 3.5). The majority of sites submitted

responses from individual professionals from each group, however a smaller number of sites had multiple respondents, although for some this was representation from multiple units within the same hospital (Table 3.6).

Table 3.3 Respondents' per hospital type separated in specialised and non specialised units

		Responses n (%)	Total n (%)
Non-specialised units	MTC	88 (40.2)	178 (81.3)
	DGH	59 (26.9)	
	TCH	31 (14.2)	
Specialised units	SIU	29 (13.2)	41 (18.7)
	SPH	12 (5.5)	
	Total	219 (100)	219

Table 3.4 Hospital size and number of level 3 beds in specialised and non-specialised units

		Non-specialised (n=178)	Specialised (n=41)	Missing responses (%)	p
Hospital bed number	>500	135 (75.8)	17 (41.5)	0	<.001
	<500	43 (24.1)	24 (58.5)		
Level 3 bed number	>10	115 (65.7)	14 (36.8)	6 (2.7)	.001
	<10	60 (34.3)	24 (63.2)		

Table 3.5 Respondents professional across specialised and non-specialised units

Profession	Non-specialised (n=137)	Specialised (n29)	Missing responses n (%)	p
Nurse	48 (35.0)	7 (24.1)	53 (24.2)	.058
Doctor	46 (33.6)	7 (24.1)		
PT	18 (13.1)	9 (31.0)		
SLT	17 (12.4)	6 (20.7)		
Dietitian	8 (5.8)	0 (0)		

Table 3.6 Number of professionals per site

No. of professionals per unit	Doctor	Nurse	PT	SLT	Dietitian
1	26	31	16	13	6
2	6	4	4	2	1
3	3	4	1	2	0
4	1	1	0	0	0

Formal links to a SIU or MTC are required for clinical liaison and to facilitate prompt patient transfer. Of the staff based in non-specialised units, 96 (53.9%) reported links with a MTC, 55 (30.9%) with a SIU and 19 (10.7%) had none. There were 167 reported links to spinal outreach services, although some respondents selected links with more than one outreach service (Table 3.7). In the South of England, more respondents were linked to the London Spinal Cord

Injury Centre (LSCIC) at Stanmore (27%), followed by the National Spinal Cord Injury Centre (NSCIC) at Stoke Mandeville (24.1%) and the Duke of Cornwall Spinal Cord Injury Centre at Salisbury (6.6%). In North England, links were reported to the Princess Royal Spinal Cord Injury Centre, Sheffield (19.0%), the Golden Jubilee Spinal Cord Injury Centre in Middlesbrough (14.6%), the Midlands Spinal Cord Injury Centre, Oswestry (10.2%), the North-West Spinal Cord Injury Centre at Southport (8.0%) and the Yorkshire Regional Spinal Cord Injury Centre, Pinderfields (2.9%). Five (3.6%) respondents reported their unit had no known link to a spinal outreach service and eight (5.8%) had links to a spinal outreach teams outside England, namely Glasgow or Dublin.

Table 3.7 Non-specialised respondents links to spinal outreach teams

Access to Spinal Outreach Team	Non-specialised unit responses (n=167)
LSCIC, Stanmore	37 (27.0)
NSCIC, Stoke Mandeville	33 (24.1)
Princess Royal SCIC, Sheffield	26 (19.0)
Golden Jubilee SCIC,Middlesborough	20 (14.6)
Midlands SCIC, Oswestry	14 (10.2)
North West SCIC, Southport	11 (8.0)
Duke of Cornwall SCIC, Salisbury	9 (6.6)
Yorkshire SCIC, Pinderfields	4 (2.9)
None	5 (3.6)
Other	8 (5.8)

3.4.3 Specialised versus non-specialised units

In this section variations in responses between staff in specialised and non-specialised units are presented with regards to their approach to clinical practices with CSCI patients.

3.4.4 Clinical care pathways and medical specialisms

Staff were asked about the clinical pathways that existed within their units, with variations identified across non-specialised and specialised units (Table 3.8). There were 166 respondents, and 53 missing. More staff in non-specialised units reported having guidance for the management of ventilator-associated pneumonia (VAP) (74.5%) and non-oral nutrition (70.8%) compared to specialised units (48.3% and 58.6% respectively). In contrast, staff in specialised units had established pathways for tetraplegia (65.5%) and

paraplegia (65.5%). Compared to non-specialised units reporting 38.7% and 34.3% respectively. Significant associations were observed between unit type and care pathways for VAP X^2 (1, N = 166) = 7.79, p<.05, tetraplegia X^2 (1, N = 166) = 7.01, p=.008 and paraplegia X^2 (1, N = 166) = 9.73, p=.002.

Table 3.8 Clinical care pathways available across specialised and non-specialised units

Care pathways^ n=166	Non-specialised units N=137 n (%)	Specialised units N=29 n (%)	Missing responses n (%)	P*
VAP	102 (74.5)	14 (48.3)	53 (24.2)	.005*
Non-oral nutrition	97 (70.8)	17 (58.6)		.199
Ventilator weaning	80 (58.4)	22 (75.9)		.079
Tracheostomy	75 (54.7)	19 (65.5)		.288
Dysphagia	58 (42.3)	11 (37.9)		.662
Tetraplegia	53 (38.7)	19 (65.5)		.008*
Paraplegia	47 (34.3)	19 (65.5)		.002*
None	8 (5.8)	0 (0)		.456

^ percentages may add up to more than 100% due to multiple responses
* p value < 0.05 using Chi-Square test of association

With regards to the medical specialism that staff were associated with, the majority of non-specialised staff (83.8%) selected intensive care (Table 3.9), whereas those based in specialised units selected for SCI (57.1%) and rehabilitation (35.7%). This reflected a significant association between unit type and specialism for intensive care X^2 (1, N = 164) = 33.08, p <.001, SCI X^2 (1, N = 164) = 43.15, p <.001 and rehabilitation X^2 (1, N = 164) = 28.68, p <.001.

Table 3.9 Clinical specialism per unit type

Clinical specialism n=164^	Non-specialised units N=136	Specialised units N=28	Missing responses n (%)	P*
Intensive Care	114 (83.8)	9 (32.1)	55 (5.1)	<.001*
SCI	10 (7.4)	16 (57.1)		<.001*
Neurosurgery	17 (12.5)	5 (17.9)		.449
Respiratory	13 (9.6)	4 (14.3)		.455
Neurology	13 (9.6)	4 (14.3)		.455
Rehabilitation	5 (3.7)	10 (35.7)		<.001*
Orthopaedics	1 (0.7)	1 (3.6)		.213
Other	12 (8.8)	0(0)		.103

^ percentages may add up to more than 100% due to multiple responses
* p value < 0.05 using Chi-Square test of association

3.4.5 Respiratory management

Both unit types reported involvement of nurses, anaesthetists, PTs and SLTs, although specialised units had a greater AHP participation, demonstrating significant associations for PT X^2 (1, N = 152) = 6.42, p = 011 and SLT X^2 (1, N = 152) = 3.95, p = .047). Of interest was a higher report of no tracheostomy team in non-specialised units (32.0%) compared to specialised units (18.5%), although no statistically significant associations were identified (Table 3.10).

Table 3.10 Tracheostomy team members per unit type

Tracheostomy team members^ n=152	Non-specialised units N=125	Specialised units N=27	Missing responses n (%)	P*
Nurse	68 (54.4)	15 (55.6)	67 (30.6)	.913
PT	59 (47.2)	20 (74.1)		.011*
SLT	55 (44.0)	17 (65.4)		.047*
Anaesthetist	53 (42.4)	15 (55.6)		.212
No trache team	40 (32.0)	5 (18.5)		.164
ENT	27 (21.6)	4 (14.8)		.427
Dietitian	9 (7.2)	5 (18.5)		.065
Other	12 (9.7)	2 (7.4)		.712

^ percentages may add up to more than 100% due to multiple responses
* p value < 0.05 using Chi-Square test of association

The lead professional for ventilator weaning was mostly identified as the ICU doctor in non-specialised units (86.4%) gaining significant association with unit type X^2 (1, N = 152) = 35.28, p <.001 (Table 3.11). Other participating professionals in non-specialised and specialised settings were PT (42.4%;25.9%) and ICU nurse (24.8%;14.8%). Significant association were identified between specialised units and greater involvement of tracheostomy X^2 (1, N = 152) = 22.31, p <.001 and respiratory teams X^2 (1, N = 152) = 21.33, p <.001 in the weaning process.

Table 3.11 Lead professional for ventilator weaning

Lead for vent weaning^ n=152	Non-specialised units N=125	Specialised units N=27	Missing responses n (%)	P*
ICU doctor	108 (86.4)	9 (33.3)	67 (30.6)	<.001*
PT	53 (42.4)	7 (25.9)		.106
ICU nurse	31 (24.8)	4 (14.8)		.256
Tracheostomy team	13 (10.4)	13 (48.1)		<.001*
Respiratory team	4 (3.2)	8 (29.6)		<.001*
Other	11 (8.8)	4 (14.8)		.349
Don't know	3 (2.4)	0 (0)		.414

^ percentages may add up to more than 100% due to multiple responses
* p value < 0.05 using Chi-Square test of association

Staff in non-specialised units predominantly reported the use of a locally agreed protocol (41.6%), compared to a protocol specified by the spinal outreach teams (18.4%) or national RISCI guidance used by only 5.6% of staff (Table 3.12). A fifth of staff did not know what protocol was used and 12% reported using none. No statistically significant associations were identified between unit type and ventilator weaning protocol.

Table 3.12 Ventilator weaning protocol by unit type

Ventilator weaning protocol n=152	Non-specialised units N=125	Specialised units N=27
Locally agreed protocol	52 (41.6)	12 (44.4)
Spinal outreach team	23 (18.4)	7 (25.9)
National guidance	7 (5.6)	4 (14.8)
Don't know	25 (20.0)	2 (7.4)
None	15 (12.0)	1 (3.7)
Other	3 (2.4)	1 (3.7)

Non-specialised and specialised units reported similar level of use for weaning with cuff deflation (82.4%;96.2%), speaking valves (76.8%;88.5%), tracheostomy masks (68.0%;57.7%), fenestrated tubes (36.8%;34.6%) and suctionaid tubes (34.4%;38.5%) (Table 3.13). Vital capacity measures were used more for weaning by staff in specialised units (88.5%) compared to non-specialised staff (40.8%) indicating a significant association with unit type X^2 (1, N = 151) = 19.56, p <.001.

Table 3.13 Ventilator weaning methods by unit type

Ventilator weaning process^ n=151	Non-specialised units N=125	Specialised units N=27	Missing responses n (%)	p*
Cuff deflation	103 (82.4)	25 (96.2)	67 (30.6)	.076
Speaking valve	96 (76.8)	23 (88.5)		.186
Trache mask	85 (68.0)	15 (57.7)		.312
Vital capacity	51 (40.8)	23 (88.5)		<.001*
Fenestrated tube	46 (36.8)	9 (34.6)		.833
Suctionaid	43 (34.4)	10 (38.5)		.693
Don't know	8 6.4)	0 (0)		.185
Other	6 (4.8)	4 (15.4)		.048

^ percentages may add up to more than 100% due to multiple responses
* p value < 0.05 using Chi-Square test of association

In the absence of guidance instructing clinicians on mandatory requirement to cap or block off the tracheostomy prior to decannulation, this has led to mixed practices. There were significant associations between unit type and the routine capping off of the tracheostomy prior to dcannulation X^2 (3, N = 150) = 40.02, p <.001. Almost half of staff in non-specialised units did not routinely cap (49.2%) compared to 7.7% in specialised units. Routine capping for CSCI patients was undertaken by 76.9% of staff in specialised units compared to 16.9% of staff in non-specialised units. Both groups reported occasional use of capping, suggesting variations to practice (Table 3.14).

Table 3.14 Routine capping by unit type

Routine capping n=150	Non-specialised units N=124	Specialised units N=26	Missing responses n (%)	P*
No	61 (49.2)	2 (7.7)	69 (32)	<.001*
Yes	21 (16.9)	20 (76.9)		
Sometimes	34 (27.4)	4 (15.4)		
Don't know	8 (6.5)	0 (0)		

* p value < 0.05 using Chi-Square test of association

3.4.6 Nutrition

Staff at both unit types agreed that the decision to commence NG feeding was usually based on the inability to meet nutritional requirements orally (81.4%; 88.5%) or due to prolonged sedation (48.3%;46.2%) or intubation (51.7%; 46.2%) (Table 3.15). There was a significant association between unit type and feeding decision when tracheostomy in-situ X^2 (1, N = 144) = 33.08, p <.001.

Table 3.15 Criteria for non-oral feeding by unit type

Non-oral feeding criteria^ n=144	Non-specialised units N=118	Specialised units N=26	Missing responses n (%)	p*
Unable to meet nutritional requirements orally	96 (81.4)	23 (88.5)	75 (34)	.387
Prolonged intubation	61 (51.7)	12 (46.2)		.609
Prolonged sedation	57 (48.3)	12 (46.2)		.842
Tracheostomy in situ	33 (28.0)	1 (3.8)		.009*
Can't sit upright	15 (12.7)	4 (15.4)		.715
Infection	8 (6.8)	2 (7.7)		.868
Don't know	6 (5.1)	1 (3.8)		.790
Other	7 (5.9)	3 (11.5)		.309

^percentages may add up to more than 100% due multiple responses
* p value < 0.05 using Chi-Square test of association

When deciding on the need to transition from NG to gastrostomy (PEG) feeding, similar criteria were selected by staff at non-specialised and specialised units (Table 3.16). Ongoing swallowing problems (73.7%; 80.8%) were a primary reason followed by requirement for NG feeding for more than 4 weeks (49.2%; 61.5%). There was a significant association between unit type and advice given by SLTs X^2 (1, N = 144) = 6.26, p=.012 and dietitians X^2 (1, N = 144) = 11.48, p=.001.

Table 3.16 Criteria to transition to PEG by unit type

NGT to PEG^ n=144	Non-specialised units N=118	Specialised units N=26	Missing responses n (%)	p*
Ongoing swallowing problems	87 (73.7)	21 (80.8)	75 (34)	.453
SLT recommendation	69 (58.5)	22 (84.6)		.012*
NG in-situ 4-6 weeks	58 (49.2)	16 (61.5)		.253
Dietitian recommendation	52 (44.1)	21 (80.8)		.001*
Patient discomfort	35 (29.7)	10 (38.5)		.381
Repeated displacement	37 (31.4)	8 (30.8)		.953
Assist hospital transfer	23 (19.5)	3 (11.5)		.340
Increased nutritional need	7 (5.9)	1 (3.8)		.674
Infection risk	4 (3.4)	2 (7.7)		.320
Don't know	9 (7.6)	1 (3.8)		.492
Other	6 (5.1)	3 (11.5)		.218

^percentages may add up to more than 100% due multiple responses
* p value < 0.05 using Chi-Square test of association

Staff at all units considered a return to eating primarily following a swallow assessment (85.6%;96.2%), with similar considerations between non-specialised and specialised units about tracheostomy cuff deflation (25.4%;26.9%) and upright seating (17.8%;15.4%) (Table 3.17).

Table 3.17 Criteria to start eating by unit type

Ready to start eating^ N=144	Non-specialised units N=118	Specialised units N=26	Missing responses n (%)	p*
After swallow assessment	101 (85.6)	25 (96.2)	75 (34)	.141
Trache cuff deflated	30 (25.4)	7 (26.9)		.874
Sitting upright	21 (17.8)	4 (15.4)		.769
After ventilator weaning	16 (13.6)	1 (3.8)		.165
When able to talk	12 (10.2)	4 (15.4)		.444
At patient request	9 (7.6)	0 (0)		.146
After decannulation	6 (5.1)	1 (3.8)		.790
When NG removed	1 (0.8)	0 (0)		.638
Don't know	6 (5.1)	0 (0)		.240
Other	6 (5.1)	2 (7.7)		.599

^percentages may add up to more than 100% due multiple responses
* p value < 0.05 using Chi-Square test of association

3.4.7 Swallowing

The process of swallow screening was considered to be a role for SLTs at both non-specialised and specialised units (84.7%;96.2%). More nurses were reported to have a role in non-specialised units (57.6%) compared to specialised units (38.5%). A range of methods were reported to be employed for swallow screening across non-specialised and specialised units, including management of saliva (60.2%;65.4%), water (61.9%;53.8%) and yoghurt (37.3%;38.5%) (Table 3.18). Differences were evident between units with greater use of blue dye (43.2%;30.8%) and thickened fluids (44.1%;30.8%) by staff in non-specialised units, although this did not achieve significant levels.

Table 3.18 Methods to screen for dysphagia by unit type

Screening methods^ N=144	Non-specialised units N=118	Specialised units N=26	Missing responses n (%)	p*
Saliva	71 (60.2)	17 (65.4)	75 (34)	.621
Water	73 (61.9)	14 (53.8)		.449
Thickened fluids	52 (44.1)	8 (30.8)		.213
Blue dye	51 (43.2)	8 (30.8)		.243
Yoghurt	44 (37.3)	10 (38.5)		.911
Speaking	27 (22.9)	5 (19.2)		.685
Other	17 (14.4)	5 (19.2)		.536
Don't know	4 (3.4)	3 (11.5)		.080

^percentages may add up to more than 100% due multiple responses
* p value < 0.05 using Chi-Square test of association

The majority of staff across non-specialised and specialised units selected bedside swallow evaluation as the routine assessment used by SLTs (85.3%;88.5%). Staff at specialised units reported greater use of FEES (53.8%) and VFS (46.2%) compared to non-specialised units (31.9% and 25.0% respectively) (Table 3.19). Staff at specialised units did not routinely allow eating with cuff inflated, compared to non-specialised units (15.5%), whereas staff at both units reported occasional cuff up eating (55.2%;44%).

Table 3.19 SLT swallow assessments by unit type

Dysphagia assessment^ N=142	Non-specialised units N=116	Specialised units N=26	Missing responses n (%)	p*
BSE	99 (85.3)	23 (88.5)	77 (35)	.680
FEES	37 (31.9)	14 (53.8)		.035*
VFS	29 (25.0)	2 (46.2)		.031*
ENT Flexible nasendoscopy	9 (7.8)	2 (7.7)		.991
Don't know	9 (7.8)	0 (0)		.142
None	2 (1.7)	0 (0)		.500

^percentages may add up to more than 100% due multiple responses
* p value < 0.05 using Chi-Square test of association

3.4.8 Communication

A larger percentage of staff working in specialised units used cuff deflation (44.3%; 69.2%) and speaking valves (13.0%;23.1%) as a communication option to allow speech compared to non-specialised units (Table 3.20). No significant associations were identified.

Table 3.20 Use of cuff deflation and speaking valve for speech by unit type

Cuff down for speech n=141	Non-specialised units N=115	Specialised units N=26	Missing responses n (%)	p*
Yes	51 (44.3)	18 (69.2)	77 (35)	.080
Sometimes	44 (38.3)	4 (15.4)		
No	10 (8.7)	3 (11.5)		
Don't know	10 (8.7)	1 (3.8)		
Speaking valves^ n=141	**Non-specialised units N=115**	**Specialised units N=26**	**Missing responses n (%)**	**p***
Sometimes	66 (57.4)	14 (53.8)	77 (35)	.742
No	27 (23.5)	3 (11.5)		.179
Always	15 (13.0)	6 (23.1)		.194
After nasendoscopy	0 (0)	1 (3.8)		.035*
Other	8 (7.0)	1 (3.8)		.558

^percentages may add up to more than 100% due multiple responses
* p value < 0.05 using Chi-Square test of association

3.4.9 Professional group responses

Differences in professional responses reflected the understanding of the roles of other professionals working in critical care with CSCI patients (Appendix 9). The involvement of SLT in tracheostomy teams was reported less by doctors (13.1%) and nurses (16.3%) compared to other groups (Table 3.21), whereas SLTs reported their own involvement within tracheostomy teams more (24.2%) compared to nurses and doctors (p=.003). There was a significant association between professional groups and the lead professional for ventilator weaning with nurses (p<.001) and PTs (p=.009) reporting their own involvement more than other professionals (Table 3.22).

Table 3.21 Tracheostomy team membership by professional group

Tracheostomy team members^ N=152	Doctor	Nurse	PT	SLT	Dietitian	Missing	p[a]
Nurse	26 (24.3)	29 (21.5)	13 (17.2)	10 (15.2)	5 (22.7)	67 (31)	.827
PT	20 (18.7)	21 (15.6)	19 (21.0)	15 (22.7)	4 (18.2)		.019*
SLT	14 (13.1)	22 (16.3)	15 (19.7)	16 (24.2)	5 (22.7)		.003*
Anaesthetist	22 (20.6)	22 (16.3)	12 (15.8)	10 (15.2)	2 (9.1)		.877
No trache team	14 (13.1)	19 (14.1)	7 (9.2)	3 (4.5)	2 (9.1)		.319
ENT	6 (5.6)	11 (8.1)	6 (7.9)	5 (7.6)	3 (13.6)		.349
Dietitian	1 (0.9)	9 (6.7)	2 (2.6)	2 (3.0)	0 (0)		.059
Other	4 (3.7)	2 (1.5)	2 (2.6)	5 (7.6)	1 (4.5)		.133

^percentages may add up to more than 100% due multiple responses
[a] p value derived from Fisher's Exact Test

Table 3.22 Lead professional for ventilator weaning by professional group

Lead for vent weaning^ N=152	Doctor	Nurse	PT	SLT	Dietitian	Missing	p[a]
ICU doctor	39 (48.8)	40 (43.5)	15 (34.9)	16 (42.1)	7 (46.7)	67 (31)	.151
PT	18 (22.5)	15 (16.3)	18 (41.9)	5 (13.2)	4 (26.7)		.009*
ICU nurse	9 (11.3)	22 (23.9)	1 (2.3)	2 (5.3)	1 (6.7)		<.001*
Tracheostomy team	6 (7.5)	4 (4.3)	4 (9.3)	11 (28.9)	1 (6.7)		.001*
Respiratory team	3 (3.8)	4 (4.3)	2 (4.7)	2 (5.3)	1 (6.7)		.878
Other	5 (6.3)	5 (5.4)	3 (7.0)	2 (5.3)	0 (0)		.095
Don't know	0 (0)	2 (2.2)	0 (0)	0 (0)	1 (6.7)		1.00

^percentages may add up to more than 100% due multiple responses
[a] p value derived from Fisher's Exact Test

Methods employed for weaning showed a number of significant associations across professional groups for use of cuff deflation (p=.001), speaking valves

(p=.038) and trache mask (p=.047) (Table 3.23). Vital capacity (p<.001) was employed by a significantly greater number of PTs compared to other professional groups. Overall, dietitians reported a high rate of uncertainty (23.5%) about processes employed during weaning compared to other groups.

Table 3.23 Ventilator weaning process by professional group

Ventilator weaning process^ N=150	Doctor	Nurse	PT	SLT	Dietitian	Missing	p[a]
Cuff deflation	45 (23.8)	38 (25.7)	24 (23.1)	19 (21.3)	2 (11.8)	69 (32)	.001*
Speaking valve	42 (22.2)	34 (23.0)	22 (21.2)	18 (20.2)	3 (17.6)		.038*
Trache mask	32 (16.9)	30 (20.3)	18 (17.3)	18 (20.2)	2 (11.8)		.047*
Vital capacity	24 (12.7)	13 (8.8)	21 (20.2)	14 (15.7)	2 (11.8)		<.001*
Fenestrated tube	24 (12.7)	18 (12.2)	7 (6.7)	5 (5.6)	1 (5.9)		.107
Suctionaid	19 (10.1)	12 (8.1)	9 (8.7)	11 (12.4)	2 (11.8)		.295
Don't know	0 (0)	2 (1.4)	0 (0)	2 (2.2)	4 (23.5)		<.001*
Other	3 (1.6)	1 (0.7)	3 (2.9)	2 (2.2)	1 (5.9)		.323

^percentages may add up to more than 100% due multiple responses
[a] p value derived from Fisher's Exact Test

There was a significant association between professional groups in identifying the impact of tracheostomy cuffs (Table 3.24). More SLTs identified this as preventing cough (p=.016), but fewer SLT associated this with preventing aspiration (p<.001). Doctors and nurses felt that it permitted safe oral intake (p=0.26). With regards to routine capping prior to decannulation (Table 3.25) more PTs routinely capping than other groups (p<.001). Most dietitians (87.5%) were uncertain of common practice in their units.

Table 3.24 Impact of inflated cuff by professional group

Impact of inflated cuff^ n=150	Doctor	Nurse	PT	SLT	Dietitian	Missing	p[a]
Prevents speech	39 (34.2)	36 (30.0)	21 (33.9)	17 (33.3)	2 (18.2)	69 (32)	.032*
Effective high pressure ventilation	36 (31.6)	28 (23.3)	18 (29.0)	18 (35.3)	3 (27.3)		.083
Aspiration prevention	27 (23.7)	37 (30.8)	15 (24.2)	5 (9.8)	2 (18.2)		<.001*
Cough prevention	5 (4.4)	6 (5.0)	5 (8.1)	9 (17.6)	0 (0)		.016*
Safe oral intake	6 (5.3)	11 (9.2)	1 (1.6)	0 (0)	0 (0)		.026*
Don't know	0 (0)	1 (0.8)	0 (0)	0 (0)	4 (36.4)		<.001*
Other	1 (0.9)	1 (0.8)	2 (3.2)	2 (3.9)	0 (0)		.382

^percentages may add up to more than 100% due multiple responses
[a] p value derived from Fisher's Exact Test

Table 3.25 Routine capping by professional group

Routine capping n=150	Doctor	Nurse	PT	SLT	Dietitian	Missing	P[a]
No	26 (53.1)	22 (47.8)	7 (26.9)	7 (33.3)	1 (12.5)	69 (32)	<.001
Yes	13 (26.5)	8 (17.4)	13 (50.0)	7 (33.3)	0 (0)		
Sometimes	10 (20.4)	15 (32.6)	6 (23.1)	7 (33.3)	0 (0)		
Don't know	0 (0)	1 (2.2)	0 (0)	0 (0)	7 (87.5)		

[a] p value derived from Fisher's Exact Test

In identifying criteria for NG feeding significant associations were identified between professional groups (Table 3.26). Although the need to maintain nutritional requirements was the main criterion, a high percentage of dietitians selected prolonged intubation, prolonged sedation (p=.001) and tracheostomy in-situ (p=.025).

Table 3.26 Criteria for non-oral feeding by professional group

Non-oral feeding criteria^ n=144	Doctor	Nurse	PT	SLT	Dietitian	Missing response	p[a]
Unable to meet nutritional requirements orally	40 (42.1)	35 (31.8)	20 (35.1)	17 (30.9)	7 (29.2)	75 (34)	.890
Prolonged intubation	18 (18.9)	24 (21.8)	12 (21.1)	13 (23.6)	6 (25.0)		.084
Prolonged sedation	17 (17.9)	21 (19.1)	9 (15.8)	16 (29.1)	6 (25.0)		.001*
Tracheostomy in situ	9 (9.5)	14 (12.7)	4 (7.0)	2 (3.6)	5 (20.8)		.025*
Can't sit upright	2 (2.1)	10 (9.1)	3 (5.3)	4 (7.3)	0 (0)		.042*
Infection	3 (3.2)	3 (2.7)	2 (3.5)	2 (3.6)	0 (0)		.964
Don't know	2 (2.1)	2 (1.8)	3 (5.3)	0 (0)	0 (0)		.563
Other	4 (4.2)	1 (0.9)	4 (7.0)	1 (1.8)	0 (0)		.314

^percentages may add up to more than 100% due multiple responses
[a] p value derived from Fisher's Exact Test

The methods selected to determine oropharyngeal dysphagia varied between SLTs and other professions (Table 3.27). Non-SLT's reported a high use of thickened fluids (p<.001) and blue dye (p<.001), whereas SLTs preferred the use of saliva (p=.009) and water (Table 3.27). Highly significant associations were identified between clinical signs of oropharyngeal dysphagia and professional group (Table 3.28). SLTs selected spiking pyrexia (p<.001) whereas doctors did not recognise wet voice (p<.001) as a strong feature compared to other staff. Eating with the tracheostomy cuff inflated was routinely favoured more by doctors (22.9%) and nurses (12.2%) than SLT (5.3%) and PT (4.0%), however all staff reported employing this method on occasions (p<.001).

Table 3.27 Methods for swallow screening by professional group

Screening methods^ n=144	Doctor	Nurse	PT	SLT	Dietitian	Missing responses	P[a]
Saliva	44 (20.5)	17 (19.3)	10 (18.9)	14 (23.7)	3 (20.0)	75 (34)	.009*
Water	45 (20.9)	19 (21.6)	9 (17.0)	11 (18.6)	3 (20.0)		.364
Thickened fluids	29 (13.5)	14 (15.9)	9 (17.0)	6 (10.2)	2 (13.3)		<.001*
Blue dye	28 (13.0)	15 (17.0)	8 (15.1)	7 (11.9)	1 (6.7)		<.001*
Yoghurt	29 (13.5)	9 (10.2)	6 (11.3)	8 (13.6)	2 (13.3)		.274
Speaking	18 (8.4)	5 (5.7)	4 (7.5)	5 (8.5)	0 (0)		.326
Other	8 (3.7)	6 (6.8)	3 (5.7)	3 (5.1)	0 (0)		.842
Don't know	2 (0.9)	0 (0)	2 (3.8)	3 (5.1)	0 (0)		.236

^percentages may add up to more than 100% due multiple responses
[a] p value derived from Fisher's Exact Test

Table 3.28 Clinical signs of dysphagia across professional groups

Clinical signs of dysphagia^ N=142	Doctor	Nurse	PT	SLT	Dietitian	Missing response	P[a]
Coughing or choking	46 (18.0)	41 (16.6)	24 (15.1)	17 (12.4)	7 (14.6)	77 (35)	.368
Food suctioned from tracheostomy	45 (17.6)	37 (15.0)	23 (14.5)	18 (13.1)	7 (14.6)		.786
Aspiration pneumonia	40 (15.6)	38 (15.4)	24 (15.1)	19 (13.9)	7 (14.6)		.227
Patient complaint of dysphagia	32 (12.5)	29 (11.7)	20 (12.6)	18 (13.1)	5 (10.4)		.100
Wet voice	17 (6.6)	26 (10.5)	25 (15.7)	16 (11.7)	6 (12.5)		<.001*
Intra-oral food residue	30 (11.7)	27 (10.9)	11 (6.9)	15 (10.9)	5 (10.4)		.218
Dropping O_2 saturations	24 (9.4)	29 (11.7)	16 (10.1)	11 (8.0)	7 (14.6)		.204
Spiking pyrexia	9 (3.5)	12 (4.9)	11 (6.9)	14 (10.2)	3 (6.3)		<.001*
Patient complaint of throat pain	9 (3.5)	7 (2.8)	3 (1.9)	7 (5.1)	0 (0)		.196
Dysphagia not expected	3 (1.2)	0 (0)	0 (0)	1 (0.7)	0 (0)		.329
Other	1 (0.4)	1 (0.4)	2 (1.3)	1 (0.7)	1 (2.1)		.286

^percentages may add up to more than 100% due multiple responses
[a] p value derived from Fisher's Exact Test

Various professional groups showed some differences in identifying the criteria for SLT referral (Table 3.29). A positive swallow screen was selected more by non-SLTs whereas SLT's identified aspiration pneumonia and swallowing problems as the key factors, although no statistically significant associations were found. Dietitians strongly rated post-decannulation as a criterion (p<.001) and reported low rates of routine SLT availability (p=.022). The main swallow assessment undertaken by SLT was BSE, identified by over half of all staff (51.7%) and selected by more nurses (62.8%) than other professions (Table 3.30). The use of VFS and FEES was under recognised by other professions compared to SLT, with FEES demonstrating significant statistical association with profession (p<.001).

Table 3.29 Criteria for SLT referral by professional group

Criteria for SLT referral^ N=142	Doctor	Nurse	PT	SLT	Dietitian	Missing response	p[a]
Routine SLT	29 (41.4)	29(39.2)	9 (22.5)	13 (36.1)	2 (11.1)	77 (35)	.022*
Positive result from swallow screen	16 (22.9)	10 (13.5)	10 (25.0)	4 (11.1)	5 (27.8)		.173
Tracheostomy cuff deflation	4 (5.7)	8 (10.8)	9 (22.5)	3 (8.3)	4 (22.2)		.011*
Aspiration pneumonia	8 (11.4)	7 (9.5)	3 (7.5)	6 (16.7)	1 (5.6)		.555
Ability to sit upright	1 (1.4)	5 (6.8)	3 (7.5)	2 (5.6)	2 (11.1)		.101
Swallow problem	2 (2.9)	3 (4.1)	2 (5.0)	3 (8.3)	0 (0)		.542
After decannulation	0 (0)	5 (6.8)	0 (0)	0 (0)	3 (16.7)		<.001*
No ICU SLT involvement	3 (4.3)	3 (4.1)	0 (0)	1 (2.8)	0 (0)		.756
Refer for communication problems only	3 (4.3)	0 (0)	0 (0)	2 (5.6)	1 (5.6)		.076
Other	4 (5.7)	4 (5.4)	4 (10.0)	2 (5.6)	0 (0)		.811

^percentages may add up to more than 100% due multiple responses
[a] p value derived from Fisher's Exact Test

Table 3.30 Dysphagia assessments by professional group

Dysphagia assessment^ N=142	Doctor	Nurse	PT	SLT	Dietitian	Missing	p[a]
BSE	55 (51.4)	27 (62.8)	17 (48.6)	19 (45.2)	4 (44.4)	77 (35)	.912
FEES	23 (21.5)	6 (14.0)	8 (22.9)	11 (26.2)	3 (33.3)		<.001*
VFS	15 (14.0)	7 (16.3)	7 (20.0)	10 (23.8)	2 (22.2)		.488
ENT Flexible nasendoscopy	6 (5.6)	2 (4.7)	1 (2.9)	2 (4.8)	0 (0)		.058
Don't know	7 (6.5)	1 (2.3)	1 (2.9)	0 (0)	0 (0)		.469
None	1 (0.9)	0 (0)	1 (2.9)	0 (0)	0 (0)		.799

^percentages may add up to more than 100% due multiple responses
[a] p value derived from Fisher's Exact Test

The delivery of mouthcare was predominantly done by nurses (97.6%) but wider involvement was reported by SLTs (63.2%) and PTs (52.0%) (Appendix 9). Nurses preferred using a daily assessment with tool whereas non-nursing staff reported twice daily mouthcare as routine. Both nurses and SLTs provided advice on oral care frequency, technique, products and tools compared to few doctors, PTs and dietitians (p<.001) (Table 3.31).

Table 3.31 Oral hygiene advice by professional group

Oral hygiene advise^ n=142	Doctor	Nurse	PT	SLT	Dietitian	Missing respon	p[a]
No advice given	27 (40.3)	5 (4.8)	23 (85.2)	3 (6.1)	6 (75.0)	77 (35)	<.001*
Frequency	10 (14.9)	27 (25.7)	2 (7.4)	12 (24.5)	0 (0)		<.001*
Cleaning products	11 (16.4)	18 (17.1)	1 (3.7)	9 (18.4)	0 (0)		<.001*
Oral hygiene protocol	10 (14.9)	22 (21.0)	0 (0)	5 (10.2)	1 (12.5)		<.001*
Effective technique	3 (4.5)	21 (20.0)	1 (3.7)	11 (22.4)	0 (0)		<.001*
Mouthcare tools	3 (4.5)	12 (11.4)	0 (0)	9 (18.4)	0 (0)		<.001*
Other	3 (4.5)	0 (0)	0 (0)	0 (0)	1 (12.5)		.099

^percentages may add up to more than 100% due multiple responses
[a] p value derived from Fisher's Exact Test

All professional groups reported using cuff deflation and speaking valves to support speech to varying degrees (Table 3.32). More doctors, PTs and SLTs reported routine use whereas a greater number of nurses said these methods were used sometimes or not at all. A highly significant association was identified between professional group and use of cuff deflation for speech X^2 (12, N = 141) = 72.84, p<.001.

Table 3.32 Cuff down for speech by professional group

Cuff down for speech n=141	Doctor	Nurse	PT	SLT	Dietitian	Missing responses	p*
Yes	28 (58.3)	15 (35.7)	17 (65.4)	8 (42.1)	1 (12.5)	78 (36)	<.001*
Sometimes	18 (37.5)	17 (40.5)	5 (19.2)	7 (36.8)	1 (12.5)		
No	1 (2.1)	9 (22.0)	1 (4.0)	2 (10.5)	0 (0)		
Don't know	1 (2.1)	0 (0)	2 (7.7)	2 (10.5)	6 (75.0)		

* p value < 0.05 using Chi-Square test of association

3.4.10 Qualitative data

Respondents were invited to contribute any final comments about the clinical management of CSCI patients. Thirty-eight comments were submitted and analysed for common themes. The following themes were identified:

i. Admission and transfer
ii. Care to CSCI patients
iii. Clinical guidance
iv. Training and staff development

i. Admission and transfer

Infrequent or short admissions of SCI patients were reported by a number of staff who considered this to have an impact on the limited development of their clinical expertise in this area. One doctor stated that the reduced frequency of admissions meant they felt "relatively inexperienced in optimal care". Comments from other staff at non-specialised units emphasised the importance of prompt patient transfer to specialised centres in order to achieve appropriate care and minimise complications due to lack of expertise. Acknowledgment of the limited beds and subsequent delays to transfer were frustrating for these staff as they were aware that specialist care was required. In the absence of an early transfer to a SIU, support would be provided by the spinal outreach team, however it was highlighted by respondents that this was not always available, leaving staff frustrated with the lack of specialist advice for ongoing management.

ii. Care to CSCI patients

For CSCI patients remaining in non-specialised units, staff reported challenges relating to consistency of care due to staff change-over in the acute setting, making care plans difficult to implement subject to changing consultants. One PT commented on "Difficulties with variability between consultant's approach, change every 3-4 days".

Throughout the survey, staff commented that care needs for CSCI patients were required to be patient-specific, due to their complexity and wide-ranging issues. A nurse added "…all patients are assessed on an individual basis. What may work for one may not work for another." This was felt to preclude the use of a protocol, as one doctor described "We have many patients with such injuries, and their care and support cannot be protocolised as all are different with differing needs!"

Most comments supported multi-professional team working, a SLT commented that although they did not have a care pathway for tracheostomy care, they did have "…up to date guidelines, a trache ward round and good MDT working". The recognition of the role of SLT in dysphagia decisions was mixed, with one doctor commenting that "SLT team now intrinsic part of ICU multi-professional

team", whereas another doctor suggested that "inappropriate SALT referrals have delayed proper eating". A PT added that "SLT can be involved but not routine as far as I know; ICU consultant will often allow eating and drinking when SIU would assess and keep patient NBM", demonstrating the conflict around decisions for oral intake.

iii. Clinical guidance

A number of respondents commented on the need for the development of national clinical guidance specifically for dysphagia management. An SLT indicated that "current tools are not sensitive enough to identify swallow impairments in this client group." Other clinical issues in SCI were highlighted as requiring further guidance, such as bowel care, cord oedema, pressure relief and positioning. This demonstrates the complexity of the caseload and need for further education and support for staff in non-specialised units.

iv. Training and staff development

In acknowledging the prolonged admissions of CSCI patients, staff commented on the subsequent need for specialist training to better support clinical care in non-specialised units. Although Outreach services often provide training to staff, a more formal approach is required to address the needs of the multi-disciplinary team. A dietitian identified the challenge for smaller AHP groups saying "currently there is little access for dietitians to gain training in SCI patients…. Often SCI courses are very focused on OT/PT and they do not meet our needs for learning."

Staff highlighted the value in developing instrumental assessment for use with all tracheostomy patients including CSCI, in order to enhance clinical management. An SLT commented "We are hoping this service will be established in the future with additional scopes and trained staff members."

3.5. Discussion

The results from this survey study have provided specific information about current clinical practices for CSCI patients with oropharyngeal dysphagia and associated impairments, across specialised and non-specialised units. This will

help to provide context for the qualitative interviews with people with CSCI about their acute hospital experiences in different units. These results will also contribute to the generation of consenus statements in the Delphi, as these variations have not been cited in literature to date. In turn this will influence the development of a screening tool that needs to be utilised by a range of staff across unit types.

Variations were evident across units and between professionals. Inconsistencies were identified in decision-making processes with gaps in knowledge about the clinical needs of CSCI patients. Although there is no current guidance on oropharyngeal dysphagia management, the national guidelines for nutritional management recommends enteral feeding for those with nutritional complications due to oropharyngeal dysphagia (National Collaborating Centre for Acute Care, 2006). Similarly, weaning guidance from RISCI considers the impact of oropharyngeal dysphagia on the process of weaning (Respiratory Information for Spinal Cord Injury, 2012). Despite these, individual members of staff make decisions at a local level with variable involvement of other disciplines or teams.

In the following discussion, the results will be considered alongside the research questions posed in the introduction (section 3.1) and the implications for CSCI patient care across specialised and non-specialised units and variations between professional roles.

3.5.1 Specialised and non-specialised units

Respondents came from a wide variety of units and clinical specialisms across UK, demonstrating the extensive range of input to acute SCI patients, rather than a focus on specialist services in MTC and SIUs, in line with national recommendations (CRG for Spinal Cord Injury, 2016). The broad representation of DGH, TCH and SPH units admitting acute SCI patient had not been previously identified. This highlights the need for extensive training and guidance for staff in these units to ensure they have the knowledge and expertise to manage the complex needs of acute CSCI patients regardless of site (National Institute for Health and Care Excellence, 2016). Only 30.9% of

respondents in non-specialised units reported having a link to an acute spinal outreach service, which is of concern, as their role is to support SCI care in these units whilst awaiting transfer. The role of outreach can differ and for some this may not include the provision of training or advice. The role and activity of outreach may be of value to explore in a future study. The following section will discuss variations between units in the care of respiratory function, oropharyngeal dysphagia and nutrition.

i. **Respiratory management**

The complex process of ventilator weaning for CSCI patients has an established set of national guidance (Respiratory Information for Spinal Cord Injury, 2012) supported by the Intensive Care Society. The survey identified that only 7% of respondents used the RISCI guidance and less than 20% used a protocol recommended by a spinal outreach service. This guidance differs from the usual wean by recommending a graduated weaning process, monitoring respiratory fatigue through measures of vital capacity. This variability has serious implication for effective CSCI weaning and increases the risk of respiratory failure (Atito-Narh et al., 2008). Details of the specific methods employed during weaning demonstrate significant variations between specialised and non-specialised units.

The use of cuff deflation, speaking valves and suctionaid tubes to support weaning was similar across specialised and non-specialised units. Staff in SIUs reported a significantly greater use of vital capacity measures during weaning compared to non-specialised units, demonstrating its importance as a measure of respiratory fatigue. A number of studies have described deteriorating vital capacity as a predictor of the need for tracheostomy (Galeiras Vazquez et al., 2013, Yugue et al., 2012), making it the single most important identifier of respiratory function in CSCI. The discrepancy in its utility would have impact on CSCI care leading to an increased risk of emergency intubation if deteriorating respiratory function is not detected and managed early (Berney et al., 2011b).

Another significant variation was the process of routine capping of tracheostomies prior to decannulation by staff in specialised units. This process allows the evaluation of upper airway patency and respiratory muscle fatigue

whilst breathing around the tracheostomy tube for a prolonged period before decannulation. A number of respondents claimed used this technique depending on patient needs. In the absence of specific guidance this leads to inconsistent practice. Early studies had suggested that the process is unnecessary for successful decannulation of CSCI patients (Ross and White, 2003, Thompson-Ward et al., 1999). Although not specified in the RISCI guidelines (Respiratory Information for Spinal Cord Injury, 2012), capping has been recommended as good practice to prevent the need for re-intubation following decannulation and detrimental impact on weaning outcomes (UK National Tracheostomy Safety Project, 2013, Braine and Sweby, 2006).

Variations were highlighted in the personnel leading the clinical management for CSCI patient especially for respiratory management. The ICU doctor, PT or nurse led decisions in MTC and TCH units. In contrast, SIU staff were more likely to use a team approach to guide the weaning process. This may be due to variations in the complexity of patients and different stages of care, with a more rehabilitative focus in the SIUs. However, increasing evidence supports an MDT approach to tracheostomy care for complex patients (Cetto et al., 2011, Cameron et al., 2009, Rozeboom et al., 2012). An integrated care pathway helps to implement this within the acute setting, so that designated roles are employed consistently.

ii. **Identifying and managing oropharyngeal dysphagia**

Overall, less than half of all units identified SLTs as leading the swallow screening process. Specialised units reported greater levels of SLT involvement followed by nurse involvement. Training nurses to screen for oropharyngeal dysphagia has been supported by previous studies, as it is recognised that they have the greatest patient contact, however no universal screening method has been agreed (Cichero et al., 2009, See et al., 2016, Speyer, 2013). To identify the presence of oropharyngeal dysphagia, staff reported using a range of screening materials. Across units, saliva and water swallows were used and staff in non-specialised units had a preference for using thickened fluids and blue dye, although these methods may not be appropriate for CSCI patients. With poor pharyngeal transit as a feature of oropharyngeal dysphagia in CSCI, (Shin et al., 2011) thickened fluids may be detrimental and there is inadequate

evidence to support its use (Andersen et al., 2013). The use of blue dye has been linked to a high rate of false negative results, which may disguise aspiration (Brady et al., 2015). Almost all staff recognised coughing and choking, food being suctioned from tracheostomy and aspiration pneumonia, as signs and symptoms of oropharyngeal dysphagia with little variations between units.

An area of contention when considering oral intake is whether to permit eating whilst a tracheostomy cuff is inflated. A greater number of staff in non-specialised units fed with cuff up, despite evidence that this may alter swallow physiology (Ding and Logemann, 2005) and does not prevent aspiration (Batty, 2009). For CSCI patients requiring long-term ventilation, cuff deflation may not be achievable so cuff-up eating has been proposed as a safe alternative (Mullender et al., 2014, Pryor et al., 2016a). To assess swallow safety, respondents in non-specialised units demonstrated less use of FEES and VFS and a greater reliance on BSE, which poorly identifies silent aspiration, relying on coughing. CSCI patients may not demonstrate a cough when aspirating due to respiratory muscles weakness, tracheostomy cuff inflation or, reduced laryngeal sensation (Shin et al., 2011). For complex tracheostomy patients the use of FEES has been recommended to identify risks and support a clinical decision (McGowan et al., 2007, Hales et al., 2008), although this appears not to be routine practice.

iii. **Nutritional management**

All staff reported availability of a care pathway for non-oral nutrition, which provided clinical guidance on nasogastric and gastrostomy feeding. For CSCI patients, early enteral feeding has been recommended as good practice in view of their high nutritional demands (Thibault-Halman et al., 2011, Dvorak et al., 2004, O'Connor et al., 2011). Staff at all units agreed that poor oral intake or prolonged intubation were criteria for requiring nasogastric feeding. However, a recent study of SCI patients transferred to SIUs reported high levels of malnutrition especially for CSCI patients with tracheostomy (Wong et al., 2012a). This suggests that clinical guidance may not be routinely applied within non-specialised units. Long-term feeding system, such as PEG, are often required, which staff at specialised units would consider based on

recommendations by SLTs and dietitians. In non-specialised units, staff based their decisions on the presence of on-going swallowing problems, depending on existing oropharyngeal dysphagia signs and symptoms, rather than risk. This requires the patient to show signs of deterioration, which may then delay or prevent PEG tube placement.

Having considered practice variations across specialised and non-specialised units, this section addresses the impact of the roles of individual practitioners in determining outcomes, particularly in the absence of clinical guidance.

3.5.2 Decision-making across professional groups

A range of multi-professional respondents participated in the study, confirming their involvement with CSCI patients. All doctors were at senior levels and a large percentage of nursing and AHP respondents were above basic grade, demonstrating a high level of clinical experience. The survey showed evidence of professional agreement on a number of clinical issues, such as criteria for commencing NG feeding, clinical signs of oropharyngeal dysphagia, use of bedside swallow assessment and use of low technology aids to support patient communication. This supports the recommendations of collaborative clinical practice in achieving beneficial patient outcomes (Wheelan et al., 2003, Reader et al., 2009). There were variations as to how decisions were made, whether by individual clinicians or teams and significant differences between professions in areas of clinical management. These will be discussed further under clinical headings with consideration of the potential impact on clinical care to CSCI patients.

i. Respiratory management

Respiratory management of CSCI patients is essential for life-preservation, and the survey shows that doctors, nurses, PTs and SLTs broadly agree on the priorities and methods for weaning. Although national CSCI weaning guidance has recommended the use of vital capacity (Respiratory Information for Spinal Cord Injury, 2012), professionals varied with their reported use of this. PTs had a greater awareness and role with utilising vital capacity, but other clinicians did not have the same level of awareness. The use of fenestrated tubes was preferred by doctors and nurses, despite a reported national decline in use following granulation risks (Braine and Sweby, 2006) and a contra-indication for

patients at risk of aspiration (Frank et al., 2007). The process of capping varied according to profession, with a preference by PTs to cap. Shared understanding of the components of tracheostomy tubes and their impact is essential for optimum care for patients (UK National Tracheostomy Safety Project, 2013). Variations in knowledge and skills may lead to a conflict of care if goals are not agreed as a team.

ii. **Dysphagia management**

To determine the presence of oropharyngeal dysphagia, respondents demonstrated a reliance on signs and symptoms, rather than anticipated risks. Non-SLT professionals used coughing and choking, food expectorated from tracheostomy and aspiration pneumonia as strong indicators of oropharyngeal dysphagia compared to SLTs. Of interest, more PTs selected wet voice as a sign of oropharyngeal dysphagia, which may reflect their role in respiratory auscultation. For SLTs, spiking pyrexia was a significant sign that may be linked to their late involvement when such symptoms are established. There needs to be caution when interpreting these clinical signs as the incidence of pyrexias in SCI patients can frequently occur with unknown causes (Savage et al., 2016).

The management of cuffed tracheostomies is contentious and was demonstrated in the survey results when all professions except SLT claimed that cuffed tracheostomy tubes prevented aspiration. This was often associated with a decision to permit oral intake when the cuff was inflated. A number of studies have recommended the use of instrumental assessment to better identify risks of aspiration (McGowan et al., 2007). A recent study of mixed patient groups, demonstrated varied needs and decisions based on the primary diagnosis rather than tube status, with SCI patients taking oral intake with cuff up (Pryor et al., 2016a). More evidence is needed in this area. Instead, SLTs had a preference for suctionaid tubes for subglottic clearance of aspirated secretions, although nurses showed the least preference for them. This variation may be associated with SLTs dealing with patients with secretion management issues, rather than a large general cohort familiar to nurses.

To assess swallowing, doctors and nurses had a preference for using thickened fluids, despite a lack of guidance supporting its use in this way. Modified fluids

are an intervention strategy for those with a specific delay to swallow initiation identified in formal assessments (Andersen et al., 2013). This demonstrates a misconception of the role of SLT and use of thickened fluids in oropharyngeal dysphagia. The use of blue dye was also a preferred screening test for aspiration chosen by doctors and nurses, despite recent recommendations cautioning against using this method due to its unreliable results (UK National Tracheostomy Safety Project, 2013). The use of FEES as an instrumental assessment was under-reported by all professional groups except SLTs, which demonstrates that although it is an established assessment method for over 15 years (Langmore, 2001) its use is not widely recognised within ICU. In this setting it contributes significantly to the evaluation of pharyngeal, laryngeal and swallowing function in patients with a risk of silent aspiration, helping to influence outcomes (McGowan et al., 2007, Hafner et al., 2008). This would be beneficial for CSCI patients with limited mobility and predominantly pharyngeal stage swallow dysfunction.

With such variable practices and knowledge of oropharyngeal dysphagia screening and assessment across professionals, clinical decisions that are undertaken by individual professionals are likely to be inconsistent. These survey findings support the need for established MDT practices, supported by training and education on oropharyngeal dysphagia management and unambigious clinical guidance. This will enable each member of the team to understand the role of others and make decisions as a team.

iii. **Mouthcare**

Good oral hygiene is linked to a reduction in VAP, with ventilated patients a high risk (Shi et al., 2013, Chen et al., 2013). In addition to nurses, over half of PTs and SLTs reported being involved in the delivery of mouthcare. For PTs this may be related to their role in respiratory care of ventilated patients. For SLTs this overlaps with their work on communication and swallowing with many also providing advice on oral care frequency, technique, tools and products to reduce aspiration pneumonia (Pace and McCullough, 2010). Although nurses led in their involvement of oral hygiene, the range of frequencies reported varied with proposals for care to be delivered six hourly, four hourly, twelve hourly or dependent on patient need. No guidance has specified frequency

although use of an assessment tool is considered best practice (Ames et al., 2011, Prendergast et al., 2013, Berry et al., 2007). Studies of oral hygiene in acute CSCI patients are limited, however long term issues have been highlighted due to physical restrictions of toothbrushing and systemic effects of xerostomia (Sullivan, 2012, Sullivan et al., 2013, Yuen et al., 2009). Good early oral care helps to establish good routines and maintain oral health.

iv. **Communication**

Speech is the quickest and most effective form of communication but restricted for those who are ventilated. An option favoured more by SIU staff was the use of leak speech and speaking valves as this directs airflow into the upper airway (MacBean et al., 2009). However, this method cannot always be employed in trauma units with different types of ventilators that do not allow leaks patients and patients are still medically unstable. Instead, low technology methods, such as communication boards or mouthing were mostly used to support patient communication, which helps to alleviate frustrations and engage in care (Patak et al., 2006, Grossbach et al., 2011). SLTs used high technology electronic communication aids more than other groups, which may be due to their direct access and familiarity with these. Studies have demonstrated particular value for CSCI patients using hands-free devices (Mitate et al., 2015) and eye-gaze technology (van Middendorp et al., 2015) although these still rely on carers and training to become proficient. Further consideration should be given to the communication needs of CSCI patients, as it is an important predictor of future quality of life (Hartley, 2015).

3.5.3 Limitations

There were a number of limitations to the study. Finding suitable participants relied on snowball sampling through critical care networks, as there is no registry of staff working in critical care, particularly AHP professionals who may work across specialties. This method relied on self-selection of participants to the study and risked missing staff not linked to critical care networks, such as dietetics and SLTs. To try to overcome this, the survey was promoted to specific professional groups and to multi-professional groups through social media, which made a response rate difficult to estimate. Another limitation was the loss of 35% of respondents by the end of the survey. This may have been due to the length of survey demanding too much time or causing fatigue. As the survey

asked questions to all professional groups, some staff may have abandoned questions outside their clinical field or those they could not answer. Although there was mostly one response per profession at each hospital, some sites had more than one response for each professional group, which may have created a bias in the results. For some sites, respondents may have been from different units, such as different ICUs or an SIU and ICU, providing different perspectives. For this exploratory study, multiple responses were valuable as it may reflect both personal and professional practices within a team. In terms of processing results, some response groups had fewer than ten respondents, such as dietitians and SPH staff, limiting a judgment on significance of the results from these groups. Although these affect generalisability of the results, the survey data provides a baseline of understanding current acute practices for CSCI patients with oropharyngeal dysphagia across specialised and non-specialised units and between different staff groups. This information is transferable to current care and will help to develop future studies aimed at improving acute care for CSCI patients.

3.6. Conclusion

Based on the results of this study clinical practices used with CSCI patients vary in knowledge and consistency across units and between professionals. Generic methods of care for weaning, oropharyngeal dysphagia, nutrition and VAP are often provided in non-specialised units rather than addressing the specific needs of CSCI patients. Non-specialised units may consider their input as short-term whilst awaiting patient transfer to a SIU. However, evidence suggest that often these stays are prolonged and patients need effective interventions in the interim periods. Comments made by staff highlighted both delays to transfer to specialised units and the subsequent need for training to support better care. Staff would benefit from best-practice recommendation for CSCI patients with a clinical pathway for oropharyngeal dysphagia management. This would facilitate early identification and clinical management to reduce the impact of secondary complications. Greater cross-disciplinary working of medical, nursing and AHP staff would improve clinical outcomes for this patient group.

In the absence of empirical evidence, the survey data will contribute to the development of best-practice recommendations for the identification and management of oropharyngeal dysphagia, through an expert consensus process in a future study (study 3, chapter 5). Having highlighted the variability of acute CSCI care, the next study will examine the experiences of multiple hospital admissions for patients with CSCI and their families to provide context on the impact of varied care.

4. Study 2: The reported experiences of CSCI patients with oropharyngeal dysphagia and their family from acute care to rehabilitation

4.1. Introduction

With only 8 official SCI units and 12-16 injuries per million per year (NHS England, 2013), this equates to 780-910 injuries per year which exceeds the 375 bed capacity of the 8 specialist spinal centres in England. The survey results of staff clinical practices (chapter 3) demonstrated that people with acute CSCI are admitted and managed in over 80 critical care units across the UK. This includes both specialised and non-specialised units with evidence of variations in the clinical management of swallowing, breathing, nutrition and communication, suggesting that hospital type may influence care. Although a number of studies have reported clinician-determined clinical outcomes within different units (New et al., 2011a, Smith, 2002), little is known about the personal impact of acute non-specialised care on the process of adjustment and transition for patients and their families following CSCI.

The experiences of people with CSCI are unique as long-staying ICU patients with full cognitive awareness and high levels of physical dependency. Existing reports of patient experiences are based on people admitted to specialised units, as this is the expected clinical pathway. Studies have reported on the process of personal adjustment to the physical disability after SCI with a focus on different stages from acute injury to long-term community living (Chevalier et al., 2009, Whalley Hammell, 2007a). There have been no identified studies that capture experiences of care in non-specialised units. This would provide a personal perspective on alternative service provision and decision-making.

The period of post-acute rehabilitation appears to be crucial in supporting a person's transition from an initial loss of life biography due to a devastating physical injury to re-establishing self-identity (Carpenter, 1994, Yoshida, 1993, Bourke et al., 2015). Consistency of care has been highlighted as a contributing

factor in the recovery of hope, of which the role of staff during the rehabilitation process is an important component (Scivoletto et al., 2005, Whalley Hammell, 2007a, Angel et al., 2011).

Few studies have focused on the additional impact of those with CSCI and lack of speech (Laakso et al., 2009, Ward et al., 2016). No studies have been identified that specifically relate to the experience of oropharyngeal dysphagia or ventilation in those with CSCI. Research with other clinical groups suggests that being ventilated has significant psychological impact, with reliance on staff for support (Karlsson et al., 2012a, Prime et al., 2016). The experience of oropharyngeal dysphagia has been poorly documented even in larger patient groups, such as stroke (Carlsson et al., 2004, Ekberg et al., 2002, Jacobsson et al., 2000) although these provide insight into the disruption to life. Similarly, little is known about the impact on family members.

The aim of this interview study was to explore the lived experiences of people with CSCI who had experienced oropharyngeal dysphagia and required ventilation, from the time of injury and admission until the current period. Alongside this, family members were given the opportunity to share their experience of the same situation, especially for early periods of time when the participant had little awareness of their environment. Given the dearth of qualitative studies in this area, the next section will review the wider literature of the experiences of adjustment to SCI, being a patient in ICU, oropharyngeal dysphagia and communication problems.

4.2. Literature review

A review of the literature was undertaken using terms related to qualitative studies of the experience of SCI, tracheostomy, ventilator, critical care, oropharyngeal dysphagia and communication problems. The following databases were searched: Medline, PsycINFO and Web of Science. Reference lists were searched for further relevant articles in addition to grey literature and conference abstracts. Results of the search revealed a number of articles detailing the long-term experiences of being tetraplegic and ventilator

dependent, but few on acute CSCI patients' experiences and none that explored oropharyngeal dysphagia. As a result, related findings of other adult patient groups on oropharyngeal dysphagia, ventilation and ICU were included to provide a similar context. The review that follows covers the experience of spinal cord injury, the acute and rehabilitation environments, and the experience of oropharyngeal dysphagia and communication.

4.2.1 The experience of spinal cord injury

People undergo a sudden and dramatic change to their body following a SCI with an instant loss of movement and sensation. Qualitative studies have explored the experience of SCI from the acute injury through to long-term adjustment, trying to identify factors that enable the rehabilitation process. Early adjustment to the sudden injury was explored by Lohne (2009) through interviews with 10 SCI patients. Three themes were generated from the participants' experiences. Firstly, '*the incomprehensible shock*' whereby participants recalled the initial post-injury period as emotional, because the injuries were unexpected and the consequences were difficult to deal with. Secondly, '*the brave survivors'*, as a number of the participants recalled trying to save others in the accidents they were involved in. Finally, '*miracles, luck or coincidence'* as some participants concluded that their close call with death made them lucky whilst others considered it a coincidence. Lohne concluded that this difference in attitude would alter their reflection on the meaning of life and process of recovery.

As time passes, people must find other ways to deal with increasingly complex issues and life transitions. The importance of hope in the continuation of recovery was highlighted in an interview study with 10 people one year after their SCI to explore their experience of hope (Lohne and Severinsson, 2006). All participants expressed the need for hope for their situation to improve, even when things were at their worst they had to believe they would get better. This was described by some as inner strength or will power, and was often developed through self-belief and supported by staff. Once hope was established, participants considered how to progress their re-integration into life.

To understand how quality of life (QoL) is re-established following SCI, Whalley Hammell (2007b) carried out a meta-synthesis of seven studies. This identified 10 main concepts that demonstrated the complexity of the experience of SCI beyond physical impairment. These included both the environmental context and the impaired body, which could support or exclude people with SCI from day-to-day activities. By being occupied with activities this added value to people's life, especially if contributing to a wider event. Similarly, self-worth was rebuilt through engagement of alternative activities. These concepts highlight a wide ranging breakdown of all aspects of life following SCI, which has been termed 'biographical disruption' describing the impact of an illness on all aspects of a person's life (Bury, 1982). Whalley Hammell (2007b) concluded that recovery post-SCI was complex and a more patient-led perspective was beneficial in trying to establish quality of life during the rehabilitation process.

Following on from this, Bourke et al. (2015) detailed the experiences of rehabilitation through in-depth interviews with four SCI patients following their discharge. The authors identified three themes that helped restore the patients' 'life biography'. The first theme '*acquiring information'* reflected people's need to understand the injury and its expected impacts to help prepare for the future. According to Bourke et al, this information was often received from staff but also from peers who shared their own lived experiences. The second theme was '*regaining control*', whereby patients became responsible for making their own decisions, facilitated by staff. Thirdly, patients tried to restore '*a sense of personal narrative'* by resuming previous roles and responsibilities once they returned home. Although based on a small sample, this study captured the wider disruption to life experienced by people with SCI and the important role of rehabilitation in contributing to the adjustment process.

4.2.2 Environment

Primary admission for a person with an acute SCI is to a major trauma centre (MTC) for immediate medical stabilisation (CRG for Spinal Cord Injury, 2016). An MTC is a busy, fast-moving environment that manages seriously ill patients

for the acute episode of their care, before transfer to a local facility. Due to the complexity of SCI, people who have been diagnosed with neurological damage to the spinal cord are required to transfer from a non-specialised unit to a SIU at an early stage (National Institute for Health and Care Excellence, 2016). A report by the Spinal Injuries Association (2015) recently identified extensive delays to transfer, with negative health consequences. The definition of delayed admission varies in the literature with measures in hours (Cheng et al., 2017), days (Amin et al., 2005) and months (Scivoletto et al., 2005). Regardless of the length of time, delays tend to be reported with reference to impact on clinical outcome measures, such as complications and length of stay rather than personal experience and quality of life (Maharaj et al., 2016, Parent et al., 2011, New et al., 2011a).

To the best of the author's knowledge no studies have explored the experience of extended admissions in non-specialised units for people with CSCI. To provide a comparative insight into the experience, qualitative studies with other patient groups in ICU will be reviewed in the following section. This will include the experience of ventilation, tracheostomy and weaning (Johnson, 2004, Wahlin et al., 2006, Cook et al., 2001, Sherlock et al., 2009, Karlsson et al., 2012b). In contrast, a large number of studies have reported on the experience of those with CSCI within specialised SIUs. These include the rehabilitation process and transition into the community and will be reviewed to better understand the experience of those with SCI specifically.

CSCI patients often need ventilation for extended periods of time whilst awake. To better understand the experience of long-staying ICU patients who require ongoing mechanical ventilation, Johnson (2004) interviewed 9 patients ventilated in ICU for 7 days or more. The study highlighted the need for patients to have some control over the environment in order to support their recovery. This relied on the provision of information and effective communication from staff. Many participants reported that communication was effortful due to their lack of speech. These interviews took place after participants had recovered and been discharged home, which may have distorted their memories of the experience compared to people with CSCI who requiring ventilation and ICU care for many weeks. A more accurate record of the experience of ventilation

was reported by Karlsson et al. (2012b) who interviewed 14 ICU patients whilst they received mechanical ventilation. The interactions only lasted on average 10 minutes and were video recorded in order to capture non-verbal language, facial expressions and gestures. The participants described ventilation and suction as unpleasant experiences causing panic at times. Additionally, they reported that although having no voice made communication difficult, a regular caregiver led to more successful communication providing a degree of control over their environment.

The issue of patient empowerment within ICU is a recognized challenge for long-staying awake patients. Wahlin et al. (2006) explored personal experiences through interviews with 11 patients with mixed conditions, after they had spent at least three days in an ICU. Only five participants had needed ventilation during their admission. The participants reported that being valued, listened to, and motivated by staff provided them with control whilst supporting them during decision-making processes. With a maximum reported ICU admission time of 35 days, the length of stay was short in comparison to CSCI patients, who require prolonged ventilation (Roquilly et al., 2014, Romero-Ganuza et al., 2015). These results may not reflect the experiences of care in a fast changing trauma unit.

Tracheostomies are inserted into the airway to provide more effective ventilation after more than a few days requirement. To understand the experience of having a tracheostomy in-situ for several weeks, Sherlock et al. (2009) interviewed eight patients whilst still in hospital. Four themes were identified: *physical sensations; understanding; information; experiences after tracheostomy removal*. Participants recalled the experience of discomfort and emotional distress despite understanding the need for a tracheostomy, often linked to survival. They reported frustration as a result of not being able to communicate, and failed attempts at alternative methods, such as mouthing. For six participants who were successfully weaned from ventilation and had their tracheostomy removed, they continued to experience a sense of fear of not being able to breathe.

Ventilator weaning may be considered for CSCI patients with injuries at C4 or below to enable them to breath independently, although a high risk of failure has been reported (Call et al., 2011, Kornblith et al., 2013, Wallbom et al., 2005). Reports on the personal experience of weaning for SCI patients have not been identified, however a systematic review of studies on the experience of weaning in a mixed patient group (Cook et al., 2001) identified five studies that used in-depth interviews to capture patient experience. These reported feeling frustrated, hopeless, uncertain, fearful, and lacking control during the weaning process. This may have been caused by or contributed to weaning failure. As weaning success was usually measured in time to ventilation independence, patient distress was seldom considered or managed. According to this systematic review, nursing staff improved the process through support and provision of information to participants.

The transition from an ICU to another unit is a part of many patients' journey, including those with CSCI. Uhrenfeldt et al. (2013) captured a number of common themes in a meta-synthesis of 14 studies focused on patients' experiences of transfer both within and across hospitals. Patients reported feeling a lack of control and anxiety, especially if the place they were going to was unknown, or they were to be separated from family members during the process. For those transferring out of ICU to a ward, this was considered a part of the recovery process for which they experienced relief at getting better. Staff played a key role by providing information about the new place and offering expressions of support. In contrast, transfer has also been viewed as a transition into 'insignificance' whereby the familiar environment was gone and participants had to do more for themselves, particularly with reduced staffing levels (McKinney and Deeny, 2002, Chaboyer et al., 2005). These studies have reported both positive and negative experiences of transfer from ICU to a ward or rehabilitation unit. The experience of transferring to a further non-specialised unit to wait for admission to a specialised unit, has not been explored in the literature and this remains a particular issue for people with CSCI (Spinal Injuries Association, 2015).

Ongoing specialised SCI rehabilitation has been considered important for the process of recovery and adjustment for those with a SCI (Maharaj et al., 2016,

Middleton et al., 2014). A number of qualitative studies have focused on the experience in specialised SCI rehabilitation reporting both positive and negative perspectives. Lucke (1999) interviewed 22 SCI patients between 2 weeks and 6 months after injury about their nursing care. Participants expressed positive feelings of being cared for and supported whilst being able to take control of decisions and develop a sense of independence. This highlighted the importance of establishing new partnerships with staff to help develop a sense of self whilst in hospital. In a study on longer-term reflections of the overall rehabilitation experience, 19 people with SCI were interviewed about their hospital experiences two years after discharge (Sand et al., 2006). Participants described the environment as challenging and reported being given limited information about their injury and receiving inadequate care. There was a reported lack of consultation about decisions and they felt that this had an impact on their sense of loss and adjustment, although in time this resolved. Despite the differences between these two studies, both highlight the value of exploring patient experience to help identify their rehabilitation needs.

Only one study is known to have captured the experience of people with SCI after admission to a specialised unit following transfer from a non-specialised unit. Garrino et al. (2011) interviewed 21 SCI patients after moving from an acute hospital to a SIU where an integrated and personalised rehabilitation programme was provided. Participants reported a rapid and intense adaptation to an environment with other SCI patients, which raised their awareness of the previously limited rehabilitation in the acute setting. New trusting relationships had to be developed with staff, who treated the participants as individuals giving them choices. This further supports the findings of Lucke (1999) and Sand et al. (2006) who underline the importance of staff who provide greater support and encouragement in the specialised setting. The authors emphasised the associated value of early rehabilitation in this ‘close-knit community’ who go on to provide long-term support.

The role of staff is just one aspect that contributes to the experience of specialised rehabilitation. In a meta-synthesis of eight qualitative studies by Whalley Hammell (2007a), the patient experiences of rehabilitation generated seven concepts that explored wider factors. These included the value of specific

staff qualities, rehabilitation context and content. Other enabling factors included peer support, meeting the needs of the real world and being able to plan for a future life. This synthesis reflected the importance of both caring, supportive staff and a patient-focused environment for the effective achievement of rehabilitation goals. This concept was supported by a later study by Angel et al. (2011) that employed both observations and interviews with 12 newly injured SCI patients. Patients reported their own struggle through rehabilitation, which the authors interpreted as either a positive or negative fight. A positive fight involved patients battling alongside staff for their recovery with a shared goal for a new future. A negative fight was created when there was disagreement between staff and patients on the goals set, and a loss of staff support in achieving a personal objective. At times, this meant that patients had to change their own goal to regain staff support, which was felt to be a compromise. In summary, patients benefit from an environment with a rehabilitation philosophy, which is as important as the role of staff in that unit, in supporting recovery post-SCI.

Another factor that restricts the recovery process is paternalism, which is seen as disrupting the discovery of a new identity for a person with SCI (Carpenter, 1994). To investigate levels of paternalism and patient participation in SCI rehabilitation, Pellatt (2004) interviewed 30 healthcare staff and 20 SCI patients in a UK spinal unit. Despite staff considering they were involved in partnerships with their patients, a paternalistic attitude was evident whereby the professionals would make decisions and encourage patients to accept them. Patients reported being satisfied with the care they received in the spinal unit, especially in preference to a non-specialised unit. The authors identified a link between the high level of staff expertise and increased paternalism that risked poor problem-solving skills being developed for future challenges. A further study concerning bladder management of SCI patients, found a predominantly paternalistic approach to decision-making by staff, particularly for those with tetraplegia (Engkasan et al., 2015), suggesting a greater risk of loss of empowerment and control for people with high levels of physical dependency. Despite having intact cognitive function and communication skills, those with tetraplegia had decision made for them without consultation.

In summary, studies to date have identified the importance of staff support in any setting to help a patient's recovery process. Furthermore, a specialised rehabilitation setting provides an enhanced environment to enable patients' short and long-term adjustment to SCI.

4.2.3 Symptoms

i. Oropharyngeal dysphagia

The presence of oropharyngeal dysphagia in CSCI patients has been reported in a number of studies (chapter 2) however none have reported on the lived experiences. In a wider review of qualitative studies capturing the experiences of oropharyngeal dysphagia, a number of impacts have been reported, namely physiological, emotional and social. These studies provide valuable insight into the significance of returning to oral intake for people with oropharyngeal dysphagia, even after short periods of time.

The physiological consequences of not eating and drinking include the sensations of dry mouth, thirst and hunger despite the provision of alternative enteral support (Nelson et al., 2004). Studies of the experience of being mechanically ventilated and nil by mouth in ICU have linked these with high levels of thirst, hunger and associated distress (Li and Puntillo, 2006, Stotts et al., 2015). The accounts of patients returning to oral intake in ICU have been very limited. A qualitative study by Segaran (2006) interviewed eight patients with tracheostomy and a range of neurological diagnoses who resumed eating and drinking whilst in ICU. Many participants reported a preference for drinks rather than food due to their dry mouth. All participants reported relief when resuming oral intake as it symbolised a return to normal routines whilst reducing the need for technology and tubes.

Two studies have underlined the complex psychological and emotional nature of eating difficulties in stroke patients. Jacobsson et al. (2000) interviewed 30 stroke patients within 2 weeks of admission to identify the acute experiences of swallowing problems. Participants reported great difficulty in adjusting to severe swallowing problems and a sense of humiliation and shame attached to the need for a feeding tube. Carlsson et al. (2004) interviewed three stroke patients

about their experiences of long-term eating difficulties. Participants expressed a sense of fear with a threat to hope in the early stages. This was followed by a process of loss with adjustment to diet adaptations and dependency at mealtimes. During the gradual process of a return to eating however, participants felt abandoned by nurses who were unable to help retrain swallowing function.

The social impact of oropharyngeal dysphagia was described as an unrecognised handicap following a questionnaire study with 30 subjects, all of whom had experienced oesophageal oropharyngeal dysphagia study by Gustafsson and Tibbling (1991). Many of the participants rated being able to eat and share mealtimes as a high priority and reported that having oropharyngeal dysphagia reduced their self-esteem and impacted on all aspects of their life. Using the same questionnaire, Ekberg et al. (2002) carried out a Europe-wide study of 360 elderly patients with oropharyngeal dysphagia to better identify the social and psychological burden. Participants reported a range of eating difficulties with 55% needing to alter their diet, and only 45% considered eating to be an enjoyable experience, suggesting reduced quality of life. Finally, 41% reported that they experienced anxiety during mealtimes with a third avoiding eating with others, increasing their risk of social isolation. These are often hidden emotions that clinicians are unaware of and little support is provided to address these concerns.

ii. **Communication problems**

To investigate the communication experiences of patients in ICU, a number of reported studies have interviewed those who are ventilator-dependent with a tracheostomy (Patak et al., 2004, Happ et al., 2011, Magnus and Turkington, 2006, Carroll, 2004, Karlsson et al., 2012b). Although these studies do not include people with CSCI, a wider review contributes to an increased awareness of their potential experiences whilst being ventilated.

Studies of patient communication have linked success with the level of staff support. Carroll (2004) identified five themes following a metasynthesis of 12 studies of patient experience of communicating whilst being non-vocal on

ventilation. Three themes described participants' communication attempts: *'not being understood', 'loss of control',* and *'negative emotions'*. Two themes detailed the care participants felt would help, namely *'individualised care'* and a *'caring presence'*. This review suggests that non-vocal patients had a predominantly negative experience of ICU that could be improved with better awareness and support from staff. Patak et al. (2004) interviewed 29 patients following extubation and 62% reported a high level of frustration during the communication process whilst ventilated. These feelings lessened when staff showed behaviours that were kind, attentive and informative, demonstrating the importance of their role. These studies included short-term ventilated patients who were interviewed when vocal again, however, CSCI patients often require long-term ventilation so their experiences may be similar in the initial stages but change over time.

Support from staff is dependent on their awareness of communication difficulties. Variations in the perception of communication success between staff and patients have been highlighted in a number of studies. Magnus and Turkington (2006) interviewed nine staff and eight patients about their experiences in ICU. A discrepancy in perceptions was identified, with patients often reporting negative experiences whilst staff recalled positive communication attempts. The authors inferred a widespread need for staff training and support in order to better facilitate communication attempts by patients who are non-vocal. Two observational studies provide further insights into communication attempts and the role of nurses in ICU. Happ et al. (2011) gathered video-recorded observations of 30 non-speaking ICU patients to describe their interactions. The analysis highlighted that staff initiating all communication attempts although interactions with patients were infrequent and brief. Additionally staff had control over and responsibility for effective communication. Nurses showed a lack of awareness of assistive techniques and failed to use any alternative communication devices. To gain better insight into the communication of ventilated patients, Karlsson et al. (2012b) used video-recordings with 14 participants. Most participants used writing and hand gestures with fewer using facial expression alone, although they were all able to nod and shake their head. When considering the relevance of these findings for people with CSCI, they are unable to access hand gestures as a means of

communication, so rely more on the support of staff to interpret their facial gesture.

4.2.4 Summary

People with CSCI are expected to be cared for in specialised units with staff who are familiar with the condition and can better prepare them to deal with long-term difficulties. However, the literature on the experiences of people with CSCI is limited. What exists highlights the complex issues of adjustment, that requires both personal inner strength and support from staff from the moment of injury and throughout the rehabilitation process. The relief of survival is followed by the need to maintain hope for recovery. Studies have highlighted the importance of positive staff support within a patient focused environment. It is not known how people with CSCI are cared for in non-specialised units with staff who may lack the specific skills and awareness to provide support, especially for dealing with complex issues such as swallowing and communication problems. Reported experiences of other patient groups whilst ventilated reveal a physical discomfort alongside the loss of speech, making it challenging to gain control of the environment. The additional restriction of eating and drinking adds to the sense of loss of normal daily activities.

4.2.5 Aims of study

The aim of this study was to explore the experiences of people with CSCI from their admission to ICU after their injury through to rehabilitation, with a particular focus on their experience of oropharyngeal dysphagia, ventilation, being non-vocal and non-orally fed. The objective was to understand how people with CSCI adjust to their impairments, and to explore the impact of clinical decisions in specialised and non-specialised settings. This will help service providers to better understand the needs of CSCI patients and to ensure the delivery of appropriate support and consistent care.

The research questions focus on the experiences of people with CSCI and their families, specifically:

1. What is the impact of tracheostomy and ventilation on their communication and swallowing?
2. What is the experience of being nil by mouth and unable to eat?
3. How do participants and families adjust to being unable to speak?
4. What is the impact of admission to a specialised or non-specialised unit on the rehabilitation process?

4.3. Method

Individual semi-structured interviews were selected as an appropriate method to gather participant views and experiences for thematic analysis. This permitted questions about specific topics, but also provided an opportunity to further explore wider issues mentioned by the participants.

4.3.1 Study ethics

The study gained ethics and NHS R&D approvals (IRAS ID: 129588; NRES Committee London-Stanmore REC Ref: 14/LO/1209) (Appendix 1). Most participants were unable to give signed consent due to limited upper limb function, so verbal consent was approved by the ethics committee, which was witnessed and counter-signed by a staff member or carer who was present.

4.3.2 Participant recruitment

The aim was to recruit a total of 10 people (two people from each of five sites) who had experienced a CSCI at least 3 months beforehand, and who had had swallowing problems at any stage following the injury. To be included in the study participants had to be aged over 18 years; admitted to an ICU post-SCI; have required a period of non-oral feeding; be able to recall early events and speak English. Participants were excluded if they had cognitive or language impairments, pre-existing swallowing problems or a high level of fatigue or medical problems that made it difficult to tolerate an interview process of up to 60 minutes. This was determined by the clinician at the local study site.

To recruit participants, five SIUs from across England were selected as Participant Identification Centres (PICs) with a named clinical contact, either a doctor, PT or SLT. Each site was sent details of the study: inclusion and exclusion criteria, a promotional poster for placing in any outpatient clinics, and three recruitment packs with an invitation letter and participant information sheet. The role of each PIC site was to identify suitable participants, provide them with a study pack with contact details of the author as Chief Investigator (CI). Participants were also able to volunteer themselves through email contact details on the posters.

Following an expression of interest from a participant either by email, phone or reply-paid form, the CI made contact and set a mutually convenient time and place for a face-to-face meeting for taking informed consent and conducting the interview, which would be audio-recorded. Family members and carers were invited to be present if the participant agreed to this. The site of interview was the participant's choice, to accommodate comfort and care requirements and limit the burden of transport. This was usually the current living environment, either a hospital or residential home. Arrangements were made to ensure suitable facilities for interviewing in advance of the visit, such as a screened-off bedside area or separate room.

Consent for study involvement was undertaken by the CI at the first meeting, following a process of checking each participant understood the study, their voluntary participation and agreement for the interview to be audio-recorded. The participants would verbally agree their consent if they were unable to sign and this would be signed by, either a carer or family member as a witness. Before the interview commenced, the participant was asked for biographic details: age, gender, type, level and severity of injury, dates of injury, dates of admission and discharge from each unit.

A total of nine participants were recruited for interview from across the five PICs. Table 4.1 shows the invitations to participate and recruitment numbers per site. At site 1, a change in staffing and staff roles made it difficult to identify suitable participants. At site 2, two outpatients were sent study packs and inpatients were actively invited to participate, however no expressions of

interest were received. Site 3 was the author's clinical site, so numbers were limited to patients who had had no clinical care from the author, to avoid a conflict of interest. Site 4 recruited two inpatients, one of whom had transferred to a residential home. On contact with staff at this setting, a further participant was recruited who had not been admitted to a spinal unit, this is listed as Site 6. Site 5, a large SIU, was initially able to recruit three participants through links with the SLT. One participant (INT04) was excluded after interview due to poor recall and fatigue and inability to fully participate in the interview process. After several months when recruitment from sites 1 and 2 did not generate any participants, a further two participants were identified at site 5 and interviewed 5 months after the first round of interviews.

Table 4.1 Recruitment of participants per PIC site

Site no.	Invitations to participate	Participant recruitment
1	0	0
2	2	0
3	1	1
4	2	2
5	5	5
6	1	1

4.3.3 Topic guide development

A topic guide was developed for use in the semi-structured interviews, based on issues identified in the literature related to ICU admissions and experiences of SCI, ventilation and oropharyngeal dysphagia and supported by the author's clinical experience of working with acute CSCI patients. The topic guide set out a series of open questions with prompts if recall was poor. Questions were based around the acute experience of swallowing problems, tracheostomy and ventilation, enteral feeding, communication issues and mouthcare.

A patient advisory group reviewed the interview questions prior to the study commencing. Several suggestions were made to enhance the process, firstly, to offer to include family members during the interview to support recall of early events, secondly, to make allowances for fatigue during the interview by offering rest periods, and finally to ask an additional question about how they thought

care could be improved. These amendments were incorporated into the final topic guide (Appendix 10).

4.3.4 Interview procedure

The interview was audio-recorded with an Olympus DM-901 digital voice recorder. Questions from the topic guide were asked directly to the participant by the interviewer. If present, a family member or carer contributed when the participant was uncertain of the details. If the participant had no ability to produce voice for the recording, the family member or carer spoke aloud the participant's mouthed communication. If no carer was present, the interviewer did this. Where additional views were raised, the interviewer followed the participant's lead to allow exploration of these before returning to the topic guide. Reflective field notes were made after each interview session detailing further information about the environment, participants, emotional reactions and any challenges, which provided additional context for later thematic analysis.

4.3.5 Data management

Prior to the interview, a participant ID was allocated to each person to anonymise all written and audio data. The recorded interviews were downloaded onto a password-protected laptop and uploaded onto a secure website for transcription by an external agency. Each transcript was checked by the author for accuracy against the audio recording. Any identifying details of hospitals or staff were anonymised by numbering units in the order the participants were admitted and staff names replaced by their professional role. Pseudonyms were allocated to each participant to humanise the transcripts.

4.3.6 Thematic Analysis

Thematic analysis was selected as the approach to analyse and interpret the interview data. This has been described by Braun and Clarke (2006) as a recursive rather than a linear process whereby the data is reviewed regularly in order to become familiar with it and identify further themes that represent an analysis of the data. In this study, each transcription was uploaded to Nvivo for

Mac Version 10.2.2 (QSR International) to assist with the process of coding and thematic analysis. In the initial phase audio recordings and transcripts of the first group of six transcripts were reviewed several times with notes being taken about potentially significant patterns. Following this, codes were captured from the data looking for semantic and conceptual features using the interview topic guide and 'in-vivo' data (participants' own words) as codes. Related codes were then reviewed and grouped into categories and organised as themes. These were then checked against both the coded and uncoded data to see if the themes fit and represent the data. At this point codes could be changed or new themes added. Due to recruitment issues, two further transcripts were collected five months later. These were coded using the established themes and new codes generated if needed. An ongoing iterative process continued by reviewing earlier transcripts against the newly generated codes to identify any further themes. Rigour was achieved through group analysis of transcript samples on two separate occasions alongside SLT researchers with expertise in thematic analysis.

The thematic analysis of the interview data was primarily driven by the topic guide as an overall framework, employing a deductive approach. However, where new themes emerged from the data that were not anticipated these were also captured using an inductive method. This led to a pragmatic approach to the analysis of the data and ensured capture of themes within and outside of the topic guide. An example of how themes were coding can be found in Appendix 11.

4.4. Results

4.4.1 Participant demographics

Demographics of the nine participants are shown below (Table 4.2). Participant INT04 was excluded due to inability to respond to questions. The mean age of the remaining eight participants at injury was 54 years (range 21-72 years). All injuries were at the cervical level resulting in tetraplegia. Seven (88%) had experienced a traumatic injury and one had a non-traumatic injury. Four (57%) participants with traumatic injuries were due to a low impact fall and three (43%) were high impact injuries. Of note, injuries to the younger participants were linked to sports injuries.

Table 4.2 Demographics of interview participants

Participant ID	Pseudonym	Gender	Injury level	Age at injury	Aetiology
INT01	Margaret	F	C5	67	Fall (H)
INT02	Roger	M	C2	64	Fall (L)
INT03	Arthur	M	C6	70	Fall (L)
INT04^	Thomas	M	Don't know	73	Fall (L)
INT05	Keith	M	C4	70	Fall (L)
INT06	Paula	F	C4	21	Sports injury (H)
INT07	Simon	M	C4	39	Spinal tumour
INT08	Ryan	M	C7,T3	25	Sports injury (H)
INT09	George	M	C2/Central cord syndrome	72	Fall (L)

^ Excluded from group analysis
H=high impact injury; L=low impact injury

At the time of interview, two participants were dependent on ventilators, and five had tracheostomies in-situ of which four were using speaking valves (Table 4.3). Two were unable to use their own voice either due to aphonia or because cuff inflation was required for ventilation. In these cases, the carer or interviewer lip-read and spoke their words aloud for the purposes of the recording. The mean time since injury was 12.3 months (range 5-27 months), and average time spent in ICU was 6 months (range 2-16 months). Before admission to a SIU, five of eight participants had been in two ICUs and two had been in three ICUs. One participant had not been admitted to a SIU and had continued their rehabilitation in a residential setting.

Table 4.3 Details of participant status at interview

Participant ID	Pseudonym	Respiratory + communication status at interview	Time since injury (months)	No. of ICUs pre-SIU admission (months)	Carer present Y/N
INT01	Margaret	V, T, SV	7	2 (5)	N
INT02	Roger	V, T – no speech	22	2 (16)	Y
INT03	Arthur	Normal	27	3 (8)*	Y
INT05	Keith	T, SV	8	2 (6)	Y
INT06	Paula	Aphonia	6	3 (2)	N
INT07	Simon	T, SV	18	3 (14)	Y
INT08	Ryan	Dysarthria	6	2 (3)	Y
INT09	George	T, SV	5	2 (2)	Y

V=ventilated, T=tracheostomy, SV=speaking valve; MTC=major trauma centre; ICU=intensive care unit; SIU=spinal injury unit *not admitted to SIU

Five participants were interviewed during their current episode of spinal rehabilitation, whilst three were interviewed after they had been discharged from a SIU. Four interviews took place in a ward within a screened off bed space; five interviews took place in a separate room. Two participants had no carer present and were offered the option of re-arranging a suitable interview time, but consented to proceed with the interview. The average length of interview was 41 minutes, with a range of 22-90 minutes. For interviews that took place on the ward there were interruptions from nursing staff to check on the patient, but these did not impact on the interview process.

4.4.2 Emerging themes

Although the focus of the interview questions was the experience of oropharyngeal dysphagia, ventilation, non-oral feeding and communication, the participants and carers also shared insights into their variations in care at different units. Following the procedures of thematic analysis (Braun and Clarke, 2006) the interview data generated six main themes: adjustment; transitions; "the golden opportunity"; "when you can't eat"; communication; and "in the hands of the nurses and doctors". The last theme generated three linked sub-themes. Each theme will now be presented in turn and illustrated by quotes from the participants. Further excerpts can be found in Appendix 12.

4.4.3 Adjustment

Participants spent several months in hospital and in multiple units, and a large part of time was spent adapting to the injury as well as the changing surroundings. The early time in intensive care was often the most intense experience for participants and their family members, who waited for news following emergency care and surgery. For many of the participants, early memories post-injury were blurred as they were often sedated. However, family members had very clear memories and narratives around adjustment in the time immediately following injury. Survival was often the initial consideration. Ryan's parents travelled to the hospital after his accident, waiting while he was in surgery:

> *When he got to hospital, everybody was ready. Apparently, I've heard since that, he had pretty much the best team available and everybody was available. He was in surgery for a very long time. Nobody*

thought he was going to survive… They were taking it hour by hour. (Ryan's mother)

Paula was later told by her friends and family about the events of her accident:

They told me that a policeman saw me, gave me mouth-to-mouth...The ambulance came, they resuscitated me. I think I was breathing until I got to the hospital, then I stopped…they gave me oxygen…I don't remember waking up…I couldn't move anything apart from my eyes…That's how I was communicating, I think I would blink for yes, look up for no. That was for a few days…My family told me they said I wouldn't survive. (Paula)

For some the relief of surviving was overshadowed by difficulties adjusting to a huge change in life, such as the need for ventilation, as Margaret explained:

I didn't understand anything about ventilators, and I couldn't really come to grips with all that at all. In the early stages I didn't really ask questions, and then afterwards I did, and began to understand all about it and what sort of ventilation and all the rest of it, but I didn't at the beginning…I realised I was lucky to be alive, and just stayed like that, keep still and nothing else awful might happen. (Margaret)

For all the participants and their families, being in hospital as a patient was a new and unfamiliar experience. This required adjustment to an environment where clinical decisions were taken without discussion and they did not feel they could ask questions:

Neither of us have ever been in hospital, or husband's been in once, the amount of questions we might ask were probably fairly few and far between. (Margaret)

All participants with tetraplegia received daily care and those with ventilation required a 24-hour care team. Adjusting to the needs of longer-term care was highlighted as an issue for those preparing to go home. At the time of interview, three participants had completed their rehabilitation at the spinal unit and were in long-stay residential homes, whilst five were still in a spinal unit and planning their future return to a home setting. This would need a significant physical and psychological adjustment to their lives.

We are hoping that you'll be able to come home, aren't we? I've measured the doors and decided that they'll probably need widening if you are still in your wheelchair (Keith's wife)

For many participants, adjustment equated with a return to pre-injury activities and interests with a goal of independence. For Paula, who had her injury whilst at university, it was important to complete her degree:

> *I want to finish university…I didn't know what career I wanted to go into. I still don't, so hopefully this is thinking time. (Paula)*

Whilst Ryan's aim continued to be independent living despite now needing physical assistance:

> *I have a discharge date. I'm on the housing list for a council house, so I'll be moving out now. Because I'm 25, I don't really want to be living with Mummy and Daddy anymore…I'm just trying to get some more independence back, living at home, because I can't rely on [girlfriend] to do everything for me. I have to do everything myself, or try to. I think I probably will [need carers] but at the moment I'm trying to do everything to be completely independent. (Ryan)*

Participants often spoke of the importance of support from family and friends to aid their recovery. In the acute stages, families made significant adjustments to their own lives in order to make regular hospital visits and provide support. Paula's family lived far from the spinal unit so when they couldn't visit they would phone to keep contact with her, even though her voice was very weak.

> *My mum comes twice a week, my sister comes twice a week, but they all call me every day, like twice a day… they call on the hospital phone… I have to make more of an effort [with my voice]. (Paula)*

Keith and his wife valued the support from their local community, where they had lived for many years, whilst he was still in hospital:

> *And we live in a lovely village where everybody is so…we know so many people, don't we, who have all been so supportive? (Keith's wife)*

Others reported making contact with charitable organisations to provide support or help to navigate the long-term care system. Simon's wife contacted a peer mentor, himself a ventilator-dependent person with a CSCI, to provide support for herself and her husband:

> *Well, I happened to see an advert on TV for Race for Life with Wings for Life. I looked up their website and I happened to see Matt on the website, and for some reason I rang him up at work and had a chat to him for two hours on the phone. He was really nice…we arranged a time to have another chat, and stuff. Then he came to visit Simon in hospital. He's brilliant. He's been really good. (Simon's wife)*

The theme of adjustment generated from the data focused on survival in the acute stages, through longer-term physical changes and psychological adjustment, supported by family, friends and external organisations.

4.4.4 Transitions

For all participants, their initial environment was a Major Trauma Centre or ICU which was often unfamiliar and confusing and required them to accept this transition from normal life.

> *[Hospital 1] was the most awful place on this earth. Dreadful. Everybody was in green scrubs, so you didn't know who was who…There just seemed to be all these masses of people. They didn't take any particular interest in you. You know, in green. Nobody could answer any questions. (Keith)*

Further transition to a specialised spinal unit was necessary for ongoing specialist care, however when a spinal unit place could not be secured, participants moved to a non-specialised unit to wait for a bed. This meant a change to another environment without the level of input that was needed for an unknown length of time. Roger had to wait 16 months to get a bed at a spinal unit, because of his need for ventilation, and found the late transition was a great challenge.

> *It was okay in [Hospital 1] they were not equipped to deal with spinal injuries. The plan was to transfer me to [Hospital 2], so, six months went by with no progress. They then decided to transfer me to [Hospital 2] ITU. (Roger)*

Participants reported that there was little or no consultation with them or their families as part of the decision-making process around transitioning to another unit. They expected staff to make the best decisions for them.

> *We left [hospital 3] at eight months and one day. We were told he'd be in a week when we first got there. But then he'd just had pneumonia, chest infections, urine infections, and then his lung collapsed. (Arthur's wife)*

For Simon and his wife, the long delay waiting for a spinal unit admission meant that the team at Hospital 2 had to consider alternative transfers, such as a residential home, to continue to meet his high level of care needs in the meantime. This meant another transition for the family.

> *It got to the point of 'if' [he was going to transfer to a spinal unit from hospital 2]… there were conversations about Simon not being able to stay in [hospital] because of the cost...They didn't hide the fact that he would benefit from being elsewhere. There were discussions. We were involved in the decision-making, but I suspect the decisions would have been pushed towards the 'yes' if we'd have said no. They [the hospital staff] were certainly very helpful, very good with making the decisions and discussing. (Simon's wife)*

For some, the decision to transfer to a non-specialised unit local to home was readily accepted. This helped family members transition to making regular hospital visits whilst still maintaining daily life commitments.

> *They were trying to get him…to come straight here [to spinal unit] from [Hospital 1] but…[being at Hospital 2] gave us a month without travelling, didn't it? Nearer home, which was quite nice. (George's wife)*

All participants in the study spent time in at least two ICUs before a final transition to a rehabilitation facility either at a spinal unit or residential facility. Although the transfer was expected, participants reported there was little preparation for the transition. One participant and his wife recalled,

> *They kept saying, "You are going", "Oh, there's no bed", "You are going", "There's no bed". Then they woke me up one morning, said, "You are going to [Hospital 2] now". (Keith)*

The success of transition relied on staff providing information about the unit and delivering consistent care across sites. Participants and their families expected units to be similar and commented on the differences in clinical practices. Some participants received information from members of the spinal outreach team, who helped to prepare for the change in care, whilst others received little or no information.

> *No, I didn't have a team [from spinal unit outreach service], I had [a nurse] who came. Might have been nice to have had a team because then they could have explained to me the ethos a little bit more, to just explain how it all worked…then I wouldn't have found the adjustment as difficult. I think that's something they could do here. Because they must realise the way it's done at the beginning is slightly strange. It's probably not like many other hospitals, and when you're ill anyway, that sort of thing can be very odd. (Margaret)*

Similarly variations in the essential equipment, such as feeding tube connectors were an issue highlighted by Ryan's mum:

> *It's a different system completely. And little things, even going from [Hospital 1] to [Hospital 2] the size of the tube is different. So their connections were different. So you'd think that was…[universal] hospital to hospital, so if you transfer…it was almost like they needed to get another one out. But they preferred the [Hospital 1] [tube] because that was thicker, but the connections, they needed to do something with that. (Ryan's mum)*

Reflecting on whether being at one hospital for the whole admission would have been better than multiple hospitals, Margaret, who was currently in a spinal unit said:

I think it would have been but [Hospital 1] were not going to keep me forever, they're too busy. I couldn't get a place here [at spinal unit], and I decided I wanted to come here[to spinal unit]… [Hospital 2] are there to look after you and then send you home with some ideas of what you might do, whereas here [at spinal unit] they're giving you a lot more work on how to look after yourself when you have to go home…there seems to be much more of that. Because they certainly weren't doing anything in [Hospital 2], and anybody I talked to there… they were doing their best…but there wasn't a great deal of help. (Margaret)

Similarly, Simon's wife felt there could have been more spinal injury related input during the hospital transition phase, to ensure rehabilitation continued:

I think probably having it highlighted and flagged up much more that Simon was a spinal injury, and that things aren't what they are outside of a spinal injury, and having that always ever-present in people's minds. So, you know, more attentive speech and language input in [Hospital 2] anyway. The availability of endoscopies and videofluoroscopies, and not treating [Hospital 2] as a holding station for the next place, and realising that actually, 'Let's see what we can do.' Whilst they did do a lot of seeing what we can do whilst he's not in a spinal unit, they could have done more, I think. (Simon's wife)

Following injury, participants experienced repeated transitions from multiple non-specialised acute facilities to a specialised spinal rehabilitation unit and eventually to a home environment, which would need adaptations in order to access. There was often little provision of information to help families and participants through the transition process, whilst their focus remained on admission to a spinal unit.

4.4.5 "The golden opportunity"

Two thirds of participants waited over 3 months for their 'golden opportunity' i.e. an admission to a spinal unit for ongoing specialised rehabilitation. After a wait of over 13 months in three different units, Simon and his wife were still hoping for a place at a spinal unit:

Hopefully, I think...just a hope that it might happen imminently. He was always…second on the list. 'He's second on the list. He's second on the list. He's second on the list'…he needs a spinal unit…Absolutely had to go to a spinal unit, because he wasn't talking and I just knew he could. I don't know why I knew he could. I just knew he could speak. I also knew he needed the chance. He needed the opportunity, and he needed to go to a specialist centre that would do that. He was promised the spinal unit, and I just thought, 'You keep to them. You put us on a list.' He needs to have specialist

> *treatment from people who know what they're talking about with spinal injury and I'm not giving up until he's had that. (Simon's wife)*

For most participants, the initial change from intensive care to a rehabilitation environment was challenging. Ryan transferred to a spinal unit after 3 months having had prior admissions to two non-specialised units. He remarked on the difference between the settings, with the spinal unit being:

> *Very more intense and busy (sic). The physios…are more knowledgeable, and they'll timetable. Never had a timetable before. So even if it's not just physio, I'm busy doing other things on my timetable, every single moment. They keep me very busy. (Ryan)*

Ryan's mother noticed a greater focus on developing independence after transfer to the spinal unit, despite his physical limitations, compared to the time spent in the acute units:

> *At [Hospital 2] he'd sit there, and if he needed to do something…they [would] come and get him…They never said, 'At 2 o'clock you'll be doing this.' They'd come and get him and say, "Right now we are going to do that," and take him away and do it. Here, you were given your timetable, and even if you can't do it yourself, it's up to you to ring the bell and say, 'I need to get into my chair and I need to be there at such-and-such a time.' We didn't grasp that to start with, we just assumed that it would be the same, and why wouldn't we assume it would be the same as the old hospital. So that took a while to realise that actually a lot of it is down to… it is his responsibility to get in places and to do things. If he needs help, he's got to ask for it. That was a difference. A big difference. (Ryan's mother)*

After 4 weeks of rehabilitation in the spinal unit, both Simon and his wife reported dramatic improvements to speech and swallowing:

> *They poked and prodded and did all sorts of stuff to you in the first 24 hours. Now you're speaking, aren't you? You're off the ventilator 12-14 hours a day, cuff down, speaking. You're much more in-charge of your own destiny. [Simon's wife]*

For Margaret after spending 5 months in an ICU environment, she found the move to the spinal unit difficult, despite staff raising expectations of a positive experience:

> *After having been told how wonderful this hospital is, and now I've been here for a while, it is, but I found the initial few days very difficult. It was quite odd, you know that I just got here and I was given all sorts of examinations, and the doctors who were very nice now but they seemed quite alien to me and then I had to learn early on to be hoisted into bed…I began to get worried again because I wasn't enjoying the experience here, and I was in a room of my own which is quite difficult too because you haven't got anyone to talk to. (Margaret)*

Others did not find the move to be a positive experience. Roger remarked negatively upon the staffing levels in the spinal unit and its impact on recovery:

> *[Hospital 2] ICU was near enough one-to-one, and moving to the spinal unit was grossly understaffed, a lot of agency people. Very few qualified nurses. I had less physio in the spinal unit. I think they had decided that the medical options were exhausted (Roger)*

Arthur was the only participant who was not admitted to a spinal unit and had an 8-month stay in hospital before being transferred to a residential home for rehabilitation. Despite this, he felt that a lack of early input was a lost opportunity:

> *My hands. Well, they didn't do nothing in [Hospital 3]. When I got here [residential unit], every day they were putting my splints on, but they didn't do no good. (Arthur)*

His wife added:

> *They were hot on chest care [at Hospital 3]. They were the best you could ask for. And his hands just went by the by. Because he couldn't move his arms either, I think they were thinking, well, why bother with them? I mean, he knows he isn't going to walk, but that does upset him that he can't use his hands. (Arthur's wife)*

Participants and their families understood that admission to a spinal unit would provide the best opportunities for rehabilitation and possible recovery following injury. The delay in being admitted raised expectations of success. For some this was fulfilled whilst others recognised that the prolonged delay was an opportunity lost.

4.4.6 "When you can't eat"

All participants with SCI had been diagnosed with oropharyngeal dysphagia requiring them to be nil by mouth (NBM) for a period of time. This followed an assessment of swallowing and the development of symptoms, often a chest infection, which would suggest difficulties:

> *They did give me a swallow test but immediately afterwards I got an infection, and so they took me off that [eating], having had four days of food and nothing again, and that was when it began to be really difficult, I really felt it. (Margaret)*

Many of the participant's partners had a clearer recall of the events surrounding swallow testing. Arthur's wife remembers how coughing after a water swallow test triggered the clinical decision that her husband was to be NBM:

The swallow nurse come round and they done the water test. Well, they had a bit of water and a bit of orange squash…but he'd got a chest infection at the time, so when he got it and he coughed…I mean, I still say we don't know whether he was coughing because he was swallowing, or coughing because he…got a cough. But then they decided that was it, he was never going to eat again or drink again. (Arthur's wife)

Keith's wife recalls the ongoing frustration of repeated failed swallow tests:

…they had tried giving you the swallow test with that blue dye, hadn't they, several times at [Hospital 1] and it had come through…going down into your lungs…They just did so many tests, and they said, "Well we'll see if you are strong enough to swallow now and things," and they'd say, "Oh no." And each time we got our hopes up, didn't we, and then they'd say, "Sorry, nil by mouth still," (Keith's wife)

Participants struggled with the decision of not being allowed to eat and drink. Being NBM had an impact on everyday life:

There was a time when you just passed the days but when you can't eat, it isn't the same. You know, although eating is not maybe the most important thing to…it's fairly important, even if it's only a sandwich at lunchtime,…when that's taken away, it's quite difficult. (Margaret)

…but when we asked the consultant, and I said, "But how long will this be before Keith can have anything to eat or drink, or will his swallow improve?" he said, "Not ever,"…and that was my blackest day, because Keith loves his food, don't you? It was really grim. He said, "The swallow is very difficult to come back if that's where the injury is." He said, "I don't think it will." Which was awful, I thought. You know, everything else had been taken from him. Now just the thought of food and drink has been taken as well, whatever is life going to be like? (Keith's wife)

For many of the participants who needed a tracheostomy and ventilation, they felt that this complicated the swallowing process. Roger, who was fully ventilated with a tracheostomy cuff inflated, remained NBM after 22 months although he still had hopes for recovery:

The worst part for me [is] not eating or drinking; communication is second for me because I am not a great talker. [I] know it's [swallowing function] not right, but still that's something that [I'd] love to be able to do again, eating and drinking (Roger)

Most of the participants had a repeat swallow test after which they were told their swallowing was better and they could resume eating. Margaret had her swallow reassessed at the spinal unit 6 months after being made NBM at the previous non-specialised hospital:

> *The swallow test I had here [at spinal unit] was lots of different foods and then a big X-ray screen, and so this was the first food I'd had in 6 months, and all these tiny morsels of biscuits and oranges and all sorts of things. And they told me immediately, it was absolutely fine, you know, and I got the feeling that the doctor who was there nearly said to me, "I don't know why you've been off food for so long." The way he asked me questions and things, I felt it was all rather a waste of time, but I can't be sure of that…I do wonder a bit; I think six months was far too long. I think there maybe was a time when I needed to be off food, but not as long as that. (Margaret)*

However, the process of resuming eating normal food was often gradual and dependent on service provision, which varied across different units. It was only after transfer to another unit, did Paula start to make progress

> *They [SLT at hospital 3} came more than three times a week. So first they gave me something like three scoops then soft food, porridge, mashed potato, stuff like that. But I soon moved onto normal food. I called my mum to buy me Nandos. (Paula)*

Simon's eventual return to eating after 14 months meant he was able to reintegrate with normal family mealtimes, as his wife recounted:

> *You've had croissants this morning, haven't you, or a croissant? Eating fairly routine normal stuff, and kind of eating when you want to choose to…a couple of times we've been out for meals. We've had cheeseburgers from McDonald's. (Simon's wife)*

Participants found swallowing problems to be an unexpected side effect of their injury. They were often confused and upset by the decision that they may never be able to eat again, as symptoms were often subtle and not instantaneous. They struggled to consider a life without food and were often given little or no rehabilitation in the early stages. Follow-up tests in the rehabilitation settings often indicated recovery and access to swallow rehabilitation, which for most participants resulted in a return to oral intake.

4.4.7 Communication

The communication theme included reflections on talking as well as attempts by the person with SCI to interact with the people around them. Many participants were unable to use their voice whilst being ventilated, so they had to explore other means of communication such as high and low technology communication aids, however accessibility was an issue for those with tetraplegia. Participants reported experiencing effortful or unsuccessful attempts to communicate. Keith commented about the impact of having no voice due to ventilation needs:

> *If you can't make a noise, you've lost the battle before you start…People thought I was getting cross with them, but I wasn't. I was getting cross with myself because I couldn't get the message across. (Keith)*

Ryan commented on his early attempts at communicating with his family:

> *I remember not being able to talk. And it was frustrating because I tried to talk, but nothing would come out. I got very frustrated that you [mum] couldn't understand me. (Ryan)*

Simon was unable to speak for 13 months due to needing a tracheostomy cuff inflated. His wife highlighted the importance of him being able to speak:

> *Of course whilst I care about the whole lack of movement, it's nothing compared to the lack of speech. Because, actually whilst the conversations might be short and stuff, they're still there. It's still being able to get his point of view. (Simon's wife)*

Participants reported mouthing words to communicate, but success was dependent on someone being able to lip-read effectively. A number of family members commented on tensions around communication, which sometimes had to be abandoned after several attempts:

> *He got really, really annoyed. If I couldn't understand him after two or three goes, it was, "Forget it, forget it." I think he tended to sleep a lot when people were there because he couldn't communicate. (Arthur's wife)*

At the time of the interviews, Roger continued to have no voice 22 months after his injury due to his ventilator needs. He was not using a communication aid, but had short periods of tracheostomy cuff deflation to allow speech. Although the sessions were short, Roger found them valuable:

> *They're useful to get a point across, those periods of time. Also for some visitors, 15–30 minutes cuff down session…the visitors cannot lip read. (Roger)*

Participants reported being provided with an aid to augment their communication attempts. These included simple alphabet boards, an E-tran frame or computer based systems such as a MegaBee or Ipad. All the CSCI participants were tetraplegic, which restricted upper limb function for writing, pointing or keyboard use, so success was dependent on the level of support provided by the communication partner. Keith and his wife recalled well-meaning attempts to support his communication:

> *Someone brought a computer keyboard thing that they thought you would be…But because Keith couldn't use his hands, we didn't get anywhere very much with that, did we? (Keith's wife)*

Simon relied on alternative communication for over a year. His wife remembers first using an eye-pointing system that allowed him to spell out words by first indicating a colour group, and then choosing a letter in that group:

> *We were given the E-tran board. Fairly early on you were taught with whoever it was how to use it, and then she taught that to us, how to use it… That worked very well. Very short answers, and if we did go with anything longer we started learning we've got to write it down. (Simon's wife)*

Ryan had some upper limb function to enable him to access an iPad, but there were other challenges as his mum recalled:

> *You were given an iPad as well, weren't you? He had that bracket on his bed so he could…quite early on we were using that. Before the speaking valve went on, we were actually using that as him trying to write things down. His vision wasn't brilliant at that point so he couldn't see, so it was pretty much 'what on earth did that say' sort of scenario. We tried it with paper and pen as well and some things, you know. I remember one day we couldn't get to the bottom of what it was you wanted. We were trying to get you to write it down and you just wrote down "Dad". It was the one day he wasn't there. I said, "Is it Dad you want?" He said, "Yes" So I got straight on the phone, and he was there within half an hour, I think. (Ryan's mum)*

Keith's wife felt that his lack of speech led staff to overlook the possibility of interaction with him:

> *And it was really difficult for weeks, wasn't it, trying to communicate with you. I mean, not for us, you heard what we were saying, but for you to be able to sort of tell us what you wanted or how you were feeling, it was really, really grim. And I just felt they were so busy fiddling with the machines and Keith need not have been there almost because he didn't seem to exist in their… And I can understand how vital it is to make sure all the machines are working and they are reading the right numbers and everything, but I just felt, as a person, you know, he wasn't…they didn't see him at all, even just to say, "Hello, Keith, how are you?" even if he couldn't answer, or, "I'm your nurse for today," because they only stayed one day. (Keith's wife)*

Communication was another challenge particularly for participants needing a tracheostomy and ventilation. Their partners used different methods to help communication attempts often these were basic. Those who used technology had mixed success due to their physical limitations.

4.4.8 "In the hands of the nurses and doctors"

The final theme captures participants' reliance on staff to provide information, care and support. Three sub-themes were identified: "This is it…and you'll have to accept it", staff contact and personal kindness.

i. "This is it…and you'll have to accept it"

Participants and their families reported that negative information about prognosis was difficult to deal with. Keith reported an incident when the consultant at the first unit told them:

> *They said to me, "This is it" he said, "no eating, immobile or anything else. This is it." He said, "And you'll have to accept it." (Keith)*

Similarly, Arthur's wife recalled:

> *The doctor turned round and said, "Of course you are not going to walk again. If you were going to walk again we'd have known that after six weeks." and he walked out. And I hate that doctor for the way he said it. I mean, Arthur was upset anyway. And I'd got it in my head he wouldn't by then. But to be told like that (Arthur's wife)*

Participants revealed frustration when different staff varied in their attitude towards care, such as eating or mouthcare. Simon and his wife recalled tension between them, and with care home staff as he was keen to eat and drink. He wanted his wife to negotiate with staff on his behalf because he was unable to speak:

> *I think one of the things that happened fairly early on…was we went to a friend's house for a birthday celebration, and Simon wanted to have some biscuits, which the care member at the time said he couldn't do, because he couldn't eat outside of the premises, so he was then almost, with his eyes, nudging me to do it, and putting me in a rock and a hard place, really…whilst we never pressured them to let him eat, because I wanted to respect their decisions, they were the ones responsible for him, it was a really hard place to be in, to say, "no, Simon I can't ask because these are the rules that are put in place." (Simon's wife)*

Keith recalls being nil by mouth and the discomfort of a dry mouth for which he was dependent on staff to provide relief. His experience of support was very varied:

> *You [were] very fortunate if you had any mouth care…Well, I used to plead for some water, but they wouldn't give it to me…I was saying, "Let me have a mouthful of water, I'll swill it round my mouth and I'll*

either spit it out or suction it out." And some would agree to it, some of them wouldn't. And one night, this was the crux point for me, they came in and I said, "Could I have some water, my mouth is dry?" The nurse who'd come on for the night shift said, "It says nil by mouth, and that's what it's going to be." (Keith)

ii. **Staff contact**

Participants reported that the hospital environment and processes were very unfamiliar so they relied on staff to deliver their physical care and provide information. George expressed this sentiment:

> *I just put my hands in the hands of the nurses and doctors…because when you are in a hospital you just basically rely on what they do…I knew nothing and was just in their hands and hoping that they knew what they were doing. Trusting them. (George)*

A number of participants reported positive experiences of staff sharing information that helped them understand the environment:

> *[We'd] have these weekly meetings and discuss what's going on. I don't understand them, but [consultant] has been pretty good and told me everything that was going to happen…Which was very pleasing. Without him knowing he was telling me what was the next step…They hardly told you a thing at either place [previous units]. This has been the best for getting information out of any of the doctors. (George)*

> *There was one doctor who was really good and explained in normal words. Whereas sometimes you know what doctors are like and they explain in doctor words, it was like…but then a nurse would come up and say, "Well what they meant is…" (Arthur's wife)*

Frequency of staff contact varied within units and had to change when transferring across units. Participants remarked on negative and positive impacts of staff changes on their experience. Keith and his wife felt that the lack of consistent staffing created a problem with continuity of clinical decisions:

> *Every so often somebody would appear who was obviously a consultant, who would say, "Next week you'll do this, you'll do that." Next week came and went, nothing happened. Because they were on this rota system, and a different consultant would be in charge every week…So you only saw the consultant every fourth or fifth week, by which time I'd forgotten what they'd said to me in the first place. I mean, I was told, wasn't I, towards the end – "Oh you'll be moving to rehab at [hospital 1] next week." Nothing happened. (Keith)*

iii. **Personal kindness**

Both participants and family members experienced personal kindness from staff members that was felt to be over and above their role. When Roger transferred out of hospital after 10 months his wife recalled:

> *When he was coming here [residential home], [staff member] from the spinal unit took him up to say goodbye to the [ICU] staff, and they all came running out. About a dozen of them, give him a big kiss (sic) and they were holding onto him. They kept going to see him when he was first brought in here. (Roger's wife)*

For Keith's wife, staff at their second unit showed care towards her by offering hot drinks and food, which was a different experience to their first unit, a trauma centre. This helped to support both Keith and his wife:

> *They were super. It was such a contrast…because if the tea trolley came round, they would give me a cup of tea…one of the staff nurses said, "There's always things left over. To save you going home and then cooking a meal, would you like to have what the patients are having?" So I said, "Well that would be lovely, but am I allowed to do this?" and she said, "Well it's only going to be thrown away." So I think about two nights out of all those weeks there was nothing left over. (Keith's wife)*

> *It's a lovely hospital…So kind…They gave you an evening meal… And I was pleased for her. (Keith)*

Kindnesses were not just focused on social interaction but also included a personal approach to care. After spending 2 months in his second hospital, Ryan's mum saw the staff as friends:

> *He made such good friends…they kept popping back and then they'd see him. In fact, one of the nurses took his trache out…She was on a course, I think, that day and it was due to start at 9 o'clock. She said, "No, that's the first thing I want to do." So she came in at 8 especially to do it. She took his trache out and then she said she went away and just called everybody and said, "A brilliant thing, I've got rid of the trache." Everybody was just so, so pleased, weren't they?...Almost as pleased as when you got your hair cut; they were just as chuffed about that as well. (Ryan's mum)*

After 6 months of being told he'd never eat, Keith reported how he felt he was offered a chance by the SLT at the spinal unit, who had a more positive attitude to swallowing:

> *Then we came here [spinal unit], and SLT came down and said, "I thought we ought to check on one or two things," and I said what had happened, and she said, "Well, they are so silly, it could be…perfectly alright one day and go the wrong way the next day." She said, "Your*

body will soon tell you if it's going the wrong way." So she said, "Should we try?" So I said, "Not half." So we started off with peach, pear puree, which got a bit boring, to say the least, and that went alright, so they said, "Alright, we'll move on a stage." so we moved on a stage, then we moved on another stage, and here we are….[eating] everything. (Keith)

For some, it was a particular individual that made a difference. Arthur and his wife described what was special about his favourite nurse:

On the ward that we'd spent 6 and a half months on, because he knew the nurses. His favourite nurse was there, which was good. It was actually a male nurse, surprise surprise…he was good, he'd done everything straightaway…Because he [Arthur] panics when he's got something there [chest]…if he needed a suction, because he could tell them, whereas others can't. And if he couldn't reach his bell he'd just bang on the side and then he'd, like, point…his favourite nurse was straight in there, in and out. (Arthur's wife)

Yes. He didn't say 5 minutes, 10 minutes, he came. (Arthur)

The attitudes and behaviour of staff made a significant impact on the experience of participants and their carers, who were dependent on them not only for care but also information and support. Kindness was noted as it was often unexpected and varied across the units to which they were admitted.

4.5. Discussion

This study sought to identify the experiences of people following a CSCI with respiratory impairment, oropharyngeal dysphagia and communication problems who were managed across non-specialised and specialised units. There have been few documented studies detailing the experience of being non-orally fed and non-vocal, and the adjustment following a CSCI. By highlighting the experiences of people with CSCI and their family members, this study aims to raise awareness and better inform care across units that admit CSCI patients.

The findings of this study underline how each story of rehabilitation after CSCI is unique. However, common themes emerge across each person's journey. Following injury, there is anxiety about survival, followed by adjustment to the condition as impairments stabilise. Diagnosis of SCI is followed by referral to a specialised unit, however delays to admission create frustration and concern about lost opportunities for rehabilitation. Being non-vocal with swallowing problems adds to the burden of participants waiting for specialist intervention. Transfer to non-specialised units begins a process of transition with provision of

general rather than specialist care. Both positive and negative contact with staff shape participants experiences. When admission to a specialised unit is achieved, expectations are very high but not always realised. As progress is made and hospital discharge approaches, many expressed happiness to be planning for the future, alongside an awareness of the reality of living with a CSCI.

The topic guide aimed the interview towards discussion of care following an acute CSCI. Although processes such as ventilation and enteral feeding were asked about explicitly in the interviews, the participants expressed few direct views about the process, either because they took place in the early period when participants had little awareness, or they were accepted as an essential part of clinical care to support recovery. The impact of ventilation and tracheostomy on communication was frequently reported alongside issues related to being nil by mouth and associated QoL issues. These appeared to create the most distress for participants and family members and for some were on-going at the time of interview. Conversely, a recurring feature of all participants' responses, which were not part of the topic guide, were delays to spinal unit admission, transfers to multiple unit and staff behaviour and the impact of these on their rehabilitation.

The discussion will re-visit the research questions in light of the participants' reported experiences. The challenges of being unable to speak and eat will be reviewed alongside the experiences of delays to spinal unit transfer and admission to multiple non-specialised units

4.5.1 The experience of having oropharyngeal dysphagia and being non-vocal

All participants found the experience of having oropharyngeal dysphagia an unexpected outcome of their injury. They had little understanding of the mechanism of disruption and were frequently given poor prognoses for returning to normal eating and drinking. A number of participants and family members reported that staff had inflexible rules for eating and drinking which limited oral hydration, leaving them with a loss of control. With very little literature on the personal experiences of oropharyngeal dysphagia, this study

highlights how important eating and drinking is as part of the recovery and adjustment process, as described by Lohne and Severinsson (2006). The need for control has been described as important to resume 'life biography' as part of the process of recovery (Bourke et al., 2015). Decisions about being NBM were often made by staff without patient consultation, which concurs with the reports of the paternalistic care of people with SCI (Engkasan et al., 2015, Pellatt, 2004).

For many participants who were told they were never able to eat or drink again, there was a sense of staff abandonment when no alternatives or therapy were offered as described by Carlsson et al. (2004). This further embedded a sense of loss of participants' former self (Whalley Hammell, 2007b). Although feeding tubes were accepted by many participants, one reported a sense of shame and humiliation, previously identified in stroke patients (Jacobsson et al., 2000). A number of participants were able to make a gradual return to eating and drinking following admission to a specialised unit, where they felt they were given specialist input. This contributed to their sense of a return to normality and recovery (Segaran, 2006).

Whilst oropharyngeal dysphagia was a side effect of the injury and spinal surgery, being unable to speak was a result of needing a tracheostomy and ventilation. Participants reported a number of negative consequences associated with communication problems. Many reported their frustration at not being able to express their needs verbally, particularly in non-specialised units where staff changed regularly and were less familiar with their communication attempts. Communication took much longer and family members observed fewer staff interactions when participants were non-vocal, particularly the loss of social niceties. This supports the findings of other reported experiences of ventilated patients (Carroll, 2004, Happ et al., 2011, Karlsson et al., 2012b).

Having no upper limb function resulted in the inability to access assistive communication aids, such as writing, hand gestures and electronic devices, which increased the reported sense of isolation (Radtke et al., 2011). Some participants spoke of withdrawal from their environment due to the physical and emotional effort involved in communicating and frequent failures to do so. This

links with similar findings in the literature from other patient groups in the intensive care environment, that rely on staff to support the communication experience (Magnus and Turkington, 2006, Happ et al., 2011, Patak et al., 2004).

Overall, participants reported the experience of oropharyngeal dysphagia and being non-vocal as frustrating and felt a strong need to regain these functions, as part of their return to normality. For many, eating and talking were eventually achieved although took an extended period of time, but for some these issues continued at the time of interview. The findings are supported by studies of other patient groups in intensive care with transient experiences. In contrast, people with CSCI report longer-term challenges across multiple settings leaving them increasingly dependent on others, with negative emotional consequences.

4.5.2 Issues of admission to multiple non-specialised units

All participants reported admissions to multiple units, which was not the expected trajectory of care for CSCI patients. Positive comments were made about the care in non-specialised units being valuable for emergency management, surgery and respiratory care, but not specific to spinal injury. Similarly, Luthi et al. (2011) identified that acute units addressed physical issues, whereas spinal units focused on rehabilitation. Prolonged hospital admissions meant participants were reliant on ward staff for all care. Supportive staff interactions and positive relationships were experienced in some units, although this would change when moving units resulting in negative staff experiences. The importance of consistent staff support has been shown to improve the progress through the rehabilitation process (Wahlin et al., 2006, Lucke, 1999).

As time progressed without specialised therapeutic input, there were examples of families needing to fight for a place at a SIU and rehabilitation. In some instances, this fight was supported by spinal unit staff, which gave participants hope that they were fighting for the same goal, a process described by Angel et al. (2011). Others reported that negative prognoses and delayed spinal unit transfer implied that staff felt there was little value in pursuing further intervention as change was unlikely. This reflects the importance of both staff

and patient participation to ensure successful rehabilitation (Sand et al., 2006, Lindberg et al., 2013).

There are no studies identified reporting on the consequences of non-specialised care for those with CSCI, as experienced by the participants in this study. The development of their new self-identity was reliant on the knowledge and support of specialist staff based in SIUs. Studies have suggested that long-term quality of life of SCI patients is dependent on their acute and rehabilitation experiences (Hammell, 2004, Carpenter, 1994). This requires clinicians to meet both the physical and emotional needs of patients throughout their care pathway. Multiple admissions to non-specialised units makes it difficult to provide consistent and ongoing support for those with CSCI who require prolonged rehabilitation.

Participants in this study were not admitted to a specialised unit via a MTC, as expected in the clinical pathway (National Institute for Health and Care Excellence, 2016). Instead they experienced admission to up to three different units prior to an SIU. This not only delayed access to specialist rehabilitation but also impacted on the support required to make the emotional adjustment to their injury. There was an overall sense of lost opportunity due to these delays, with oropharyngeal dysphagia and communication problems especially poorly understood and managed in non-specialised units.

4.5.3 Delays to spinal unit transfer

Reports of prolonged delays to SIU transfer were unexpected and a significant concern for participants and their families. They were frequently unaware of the expected length of delay and were given mixed messages about the wait. This links to a sense of insignificance reported in studies of participants' experiences following discharge from ICU (Chaboyer et al., 2005, McKinney and Deeny, 2002). Most participants and families were aware of the value of a SIU place, its limited capacity and the need to wait. Their concern focused on the lack of specialised rehabilitation during the period of delay, and the potential loss of recovery. This contrasts with studies describing transfer from ICU as indicative of recovery, especially when associated with staff support (Uhrenfeldt et al., 2013).

When transfer to SIU was finally achieved, some participants felt unprepared for the change in environment. They reported a dramatic difference in the intensity of input often after months of relative inactivity in the acute hospital, as reported by Garrino et al. (2011) when SCI patients transferred to a rehabilitation setting. For many participants, being in a specialised unit meant a first opportunity to participate in meaningful activity. They achieved a sense of autonomy through gaining independence and contributed to the decision-making process about discharge plans (Whalley Hammell, 2007a, Lucke, 1999).

Reflecting on the delay, participants and families felt they would have valued more information and better training of staff at non-specialised units in order to deliver spinal-relevant care earlier, a recommendation supported by NICE (2016). This highlights the important role of spinal outreach services, established to provide a link between specialised services and non-specialised units (NHS England, 2013). Contact with outreach support was available to participants and families in the early acute period, but with an average wait of 6 months, on-going contact was frequently absent. Delays to SIU admission for those with respiratory requirements were evident in this study, supporting the findings of a recent report by the Spinal Injuries Association (2015).

Overall, participants and their families found the experience of oropharyngeal dysphagia and being non-vocal challenging in addition to the physical limitations of CSCI. The expectations for specialised rehabilitation at a SIU grew whilst having to wait for transfer at multiple non-specialised units, where specialist input was varied. The role of staff and family were important in providing emotional support throughout the recovery process, which helped participants feel hopeful about discharge and future life.

4.5.4 Limitations

There were several limitations to the study in terms of recruitment and the interview process. Firstly, the study aimed to recruit ten people with CSCI and an experience of ventilation and oropharyngeal dysphagia. Local SIU staff invited suitable participants to make contact with the study lead after being

given details of the study. This required a proxy, either a carer or family member, to make contact, which may have been problematic if the study details were not shared with them directly. Also a number of CSCI patients are cared for in residential settings following discharge from SIU, and are not in direct contact with SIU staff, making recruitment a challenge. Specific reasons for non-participation of those invited to participate were not identified. This would be a valuable enquiry for future studies with CSCI patients to ensure their representation in research.

A number of the participants had no audible voice and although for many studies this is an exclusion to participation, the author felt it was important to explore the experiences of those without voice. With an inability to access any other methods of communication, lip-reading had to be used. At times it was difficult to clearly identify the message and further clarification was sought. Generally the responses were short with a family member adding further content when required. Other participants also provided short responses especially for aspects of acute care when they had little recall or awareness of events. This may have reduced the richness of data for participants' experiences but provided information on the wider family experience.

Although it is not possible to generalise these findings to the experience of other people with CSCI, it does provide insight into the impact of varied clinical care, especially in the non-specialised environment. To support methodological rigour, member checking would have been valuable, however it was considered unsuitable due to the extra demands on patients' time and effort, especially those remaining in a hospital setting. Also, there was a risk that confidentiality would be compromised if paper transcripts were sent and read out to participants by staff members caring for them.

Direct questions about quality of life were not used in this study although Hammell (2004) suggests a link between prolonged institutionalisation post-injury and reduced QOL. Further research is warranted to investigate the long-term outcomes of people with CSCI following care in both specialised and non-specialised units. With a need for tracheostomy and ventilation and its

established link with oropharyngeal dysphagia, further qualitative studies would be beneficial to understand the personal impact on people with CSCI.

4.6. Conclusion

The results of the study provide a unique insight into the experiences of CSCI patients with oropharyngeal dysphagia following injury. All participants and carers found the management of swallowing problems particularly challenging. They were often given devastating prognoses and limited interventions until transfer to a SIU. Delayed SIU transfer averaged 6 months and interim multiple ICU admissions delivered fragmented care. Rather than rehabilitation being a seamless continuum from trauma centre to spinal unit, there were variances in interventions, which disrupted recovery. Participants were exposed to environments that were not always able to provide the physical, emotional and psychological care needed for adjustment to their CSCI.

These findings support the need for staff to understand the nature of oropharyngeal dysphagia and being non-vocal better in order to provide hope, reassurance and prepare patients for rehabilitation. This could be achieved through training and improved links with the local spinal outreach teams. Changing care in non-specialised units in the absence of clinical guidance is problematic. Expert consensus is required to develop a swallow screening tool and clinical recommendations for early management of oropharyngeal dysphagia and communication. This will be explored in the next chapter.

5. Study 3: Using an e-Delphi approach to gain expert consensus on oropharyngeal dysphagia identification and management in CSCI

5.1. Introduction

Oropharyngeal dysphagia is poorly identified and managed in CSCI, leading to complications that are detrimental to health and recovery (Abel et al., 2004, Chaw et al., 2012, Wolf and Meiners, 2003, Kirshblum et al., 1999). As demonstrated in the survey of clinical practice (Chapter 3), different methods were used to identify the presence of oropharyngeal dysphagia, including thickened fluids, blue dye, water and saliva. Similarly, there were different attitudes to long-term feeding and communication options, with variations evident across specialised and non-specialised units and between professional groups. There are currently no agreed standards of care for identifying and managing oropharyngeal dysphagia in CSCI patients.

Multiple factors have been cited as contributing to oropharyngeal dysphagia, including tracheostomy, ventilation, surgery and level of injury, however, these have not been systematically applied in clinical practice. In the absence of empirical evidence, expert consensus provides a process of agreement on the standards of clinical practice required in the management of oropharyngeal dysphagia in CSCI patients. With only a small number of experts over a wide geography, collecting this information can be a challenge. For this reason, a Delphi technique was used with an electronic format to allow wide participant involvement. The information agreed by experts would help to establish best practice clinical recommendations for oropharyngeal dysphagia management.

A number of Delphi studies have been used to better inform clinical practice through expert consensus. These studies do not employ a graded literature review as there is little to base this on, instead experts are defined by their extensive clinical experience and hence their opinion is sought to establish a baseline consensus for clinical practice (McMillan et al., 2016). This has been particularly evident in the management of SCI patients, with the development of

a balance assessment (Ardolino et al., 2012), and pain management guidance (Hitzig et al., 2016). Boldt et al. (2013) used a Delphi process with an international group of nurses to identify intervention goals for nurses working with SCI patients based on the International Classification of Functioning, Disability and Health. This work contributed to a checklist of care required for SCI patients that included eating, drinking and communication impairments, not previously identified. Another example of the use of a modified Delphi was a consensus study on the applicability of an integrated nutrition pathway for acute care (Keller et al., 2015). A multi-disciplinary panel was recruited from the local area to provide validation of the pathway to enhance implementation into the clinical environment.

5.1.1 Literature review

Much of the clinical practice with SCI patients is based on empiricism, due to the absence of controlled trials, which are difficult to undertake because of the heterogeneous nature of CSCI and low frequency admissions across multiple sites. The evidence which is available is largely retrospective and focussed on care in specialised units (Brady et al., 2004, Seidl et al., 2010a, Chaw et al., 2012). In non-specialised units, general oropharyngeal dysphagia screening protocols are employed which may not be sensitive to the impairments of those with CSCI (chapter 3). Variations in clinical practice between specialised and non-specialised units has been evidenced in the literature (Smith, 2002, New et al., 2011a). This supports the need for SCI patients to receive specialist interventions. However, with a limited bed capacity in SIUs in England, prolonged admissions in non-specialised units necessitate the provision of clinical guidance to ensure consistent care.

Current literature was reviewed (chapter 2) to identify relevant topics that required agreement through expert consensus. This included factors contributing to the risk of oropharyngeal dysphagia in CSCI, the optimal methods of identification and management of oropharyngeal dysphagia. This information was linked to the survey results (chapter 3) that demonstrated variations in clinical interventions.

i. Oropharyngeal dysphagia risk factors

ii. Identification of oropharyngeal dysphagia
iii. Management of oropharyngeal dysphagia

i. Oropharyngeal dysphagia risk factors

The literature detailing oropharyngeal dysphagia in CSCI patients refers to multiple causative factors rather than one locus of damage, making this a complex clinical area for non-expert clinicians to identify. Some include pre-morbid factors, such as age and others are co-morbid, linked to the injury and medical interventions, such as surgery and tracheostomy. In a number of retrospective studies, increased age at injury was associated with increased mortality post-SCI, with the age varying from over 45 years (Watt et al., 2011, Rabadi et al., 2013) to over 60 years (Prusmack et al., 2006, Daneshvar et al., 2013) reducing survival to 50% at 1 year with pneumonia reported to be a leading cause. Similarly, some studies focussing on swallowing function post-CSCI have identified age as a contributing factor especially alongside level and severity of injury (Kirshblum et al., 1999, Shem et al., 2012a, Shin et al., 2011, Seidl et al., 2010a). A number of studies have indicated no correlation between age and oropharyngeal dysphagia, making age a questionable factor contributing to risk (Brady et al., 2004, Wolf and Meiners, 2003, Abel et al., 2004).

The level of injury has an impact on loss of innervation to upper or lower body and respiratory muscles. Damage to the cervical spinal cord at C1 to C4 results in complete loss of diaphragm innervation and is associated with an increased risk of oropharyngeal dysphagia (Kirshblum et al., 1999, Abel et al., 2004, Seidl et al., 2010a). Smaller numbers of patients with damage at C5 to C7, have reported oropharyngeal dysphagia, so it is uncertain whether their dysfunction relates to partial diaphragm function (Wolf and Meiners, 2003). Seidl et al. (2010a) had suggested that the larynx is located at C6, so damage in that area is likely to impact on swallowing. There have been no studies to verify if thoracic level injuries have an impact on swallowing function.

The severity of cord injury, described as complete or incomplete, has been linked to an increased risk of oropharyngeal dysphagia in a number of studies,

associated with a greater need for prolonged respiratory support (Brady et al., 2004, Seidl et al., 2010a, Abel et al., 2004). Other studies reported no correlation with severity of injury (Chaw et al., 2012, Shem et al., 2012a), so this remains an area of uncertainty with regards to oropharyngeal dysphagia risk.

Surgery to the cervical spine has had variable reports of impact on laryngeal function, whether elective and for traumatic injuries. Studies have reported complications following both anterior and posterior surgical approaches (Smith-Hammond et al., 2004, Brodke et al., 2003, Campbell et al., 2010). Some studies have linked this to soft tissue oedema (Kepler et al., 2012) and some to pain or reduced motion (Radcliff et al., 2013). Singh et al., (2013) identified additional risk factors contributing to oropharyngeal dysphagia as increased age, male, comorbidities and over 3 levels of surgery. This was associated with prolonged length of stay and costs.

ii. Identification of oropharyngeal dysphagia

To prevent the development of oropharyngeal dysphagia symptoms, studies have recommended early identification of risks (Brady et al., 2004, Seidl et al., 2010a) although no standard approach has been proposed. A variety of screening methods have been reported including blue dye tests, oromotor evaluations and bedside swallow assessments (Brady et al., 2015). With regards to assessment, oropharyngeal dysphagia has been focussed on laryngeal and pharyngeal impairments. In the reported studies VFS was used more frequently than FEES (Shem et al., 2012a, Shin et al., 2011, Chaw et al., 2012, Brady et al., 2004, Wolf and Meiners, 2003). These have described reduced laryngeal elevation, loss of cough and reduced laryngeal sensation (Ward and Morgan, 2009, Brady et al., 2004, Shem et al., 2012a) as well as pharyngeal disruption (Abel et al., 2004, Shin et al., 2011). One study has proposed that bedside swallow evaluation is diagnostically accurate compared to VFS (Shem et al., 2012b) although the sample size was small and a third of subjects did not have comparative assessments with VFS. BSE was reported as the routine assessment in the survey of staff clinical practice (chapter 3). Consensus is needed to determine the optimal methods for oropharyngeal dysphagia screening and assessment.

It is important to differentiate the clinical symptoms of oropharyngeal dysphagia from symptoms of other disease processes in CSCI. Chest infections and pneumonia, which are features of aspiration due to oropharyngeal dysphagia, have also been attributed to atelectasis and respiratory insufficiency (Chaw et al., 2012, Galeiras Vazquez et al., 2013). Similarly, pyrexia can be a feature of chest infections as well as bladder or wound infections or disruption to the autonomic system affecting temperature regulation (Savage et al., 2016, Beraldo et al., 1993). Clinical signs of malnutrition have also been reported as valuable in clinical practice. Serum albumin changes help to detect nutritional decline in SCI (Laven et al., 1989, Chen et al., 2014), although these have also been considered as unreliable as they can be symptomatic of other processes (Thibault-Halman et al., 2011). Obtaining consensus on signs and symptoms relating to oropharyngeal dysphagia in CSCI would contribute to a more focussed process when screening for risk.

iii. **Management of oropharyngeal dysphagia**

The clinical management of oropharyngeal dysphagia can include a compensatory or therapeutic approach and these are well documented in a number of patient groups. Compensation will not change the primary disorder but will counteract the difficulties through the use of dietary modifications (Macht et al., 2012), feeding tubes (Thibault-Halman et al., 2011, Rowan et al., 2004) or remaining NBM (Martino et al., 2009). A therapeutic approach aims to change the impairment through strengthening exercises or manoeuvres (Logemann, 2008). For patients requiring tracheostomy and ventilation, oropharyngeal dysphagia is known to impact on status of the cuff (Pryor et al., 2016a, Hernandez et al., 2013, Ding and Logemann, 2005). This affects use of speaking valves (Baumgartner et al., 2008), ventilation modes (Dikeman et al., 2008) and communication ability (MacBean et al., 2009). These studies have focussed on short term ventilated patients and there is little guidance on how to manage those with oropharyngeal dysphagia requiring long-term ventilation.

For those on modified diets or NBM, regular oral hygiene is a critical issue to reduce dry mouth and VAP (McRae, 2011, Browne et al., 2011). VAP has also been associated with supine positioning of patients with an increased risk of

aspiration of gastric contents (Hellyer et al., 2016, Drakulovic et al., 1999). This may put CSCI patients at greater risk of VAP due to the need to be supine to support respiratory function (Baydur et al., 2001). Supine positioning is thought to be unsafe for oral intake, with many assessments requiring patients to be upright (Trapl et al., 2007), if not they are often kept NBM. For CSCI patients this may last an extended period of time so swallowing safety should be considered in alternative positions (Sakuma and Kida, 2010).

The data from the survey on clinical practice (chapter 3) and qualitative interviews with CSCI participants (chapter 4) identified varied interventions and inconsistent decision-making across units and between professionals. Expert consensus is required to provide guidance on agreed methods of identification, assessment and interventions to be delivered by staff regardless of site.

5.1.2 The e-Delphi Process

The Delphi process is an iterative method of capturing the expert opinion of multiple individuals. The aim of a Delphi is to achieve consensus of opinion from experts in an area where existing evidence for clinical practice is limited, which makes it relevant to many areas of healthcare practice (Keeney et al., 2010). Statements for a Delphi study can either be generated from a questionnaire to the group, or pre-determined from a review of the relevant literature, particularly when the subject is broad (Keeney et al., 2006). A steering group with a representative sample of professionals was used to reduce bias of statements and ensure appropriate language and content for all professional groups. These statements are then sent to an expert panel to rate their preference using a Likert scale. Consensus of opinion is sought and this is usually set at a percentage level. At the end of each round, those statements that achieve a pre-determined level of group consensus are retained whilst those without agreement are either discarded, modified or sent back to the group for further rating. The iterative process continues until either consensus is reached for the remaining statements or no further changes are generated. This is expected to happen over two to four rounds depending on the heterogeneity of the expert panel (Hasson et al., 2000, Mullen, 2003). In its electronic format, the e-Delphi

can access a wider group of participants more quickly without geographical restrictions (Meshkat et al., 2014).

The following features are key to the Delphi process and will be discussed individually with reference to the current study (von der Gracht, 2012, Goodman, 1987, Okoli and Pawlowski, 2004):

- Recruitment of an expert panel
- Anonymity of responses made by individual panel members
- Controlled feedback after each round
- Achieving rigour

5.1.3 Expert panel recruitment

An expert is defined as a person with extensive experience, knowledge or familiarity with the specific area being sought. Selection of an appropriate panel is of importance to achieving a level of consensus (Coulter et al., 1995, Campbell et al., 1999) however, there is debate about the value of homogenous compared to heterogeneous groups and associated panel sizes. Heterogeneous panels may make consensus more difficult to achieve adding complexity to data analysis (Skulmoski et al., 2007). Others suggest that a mixed panel enriches the data, making the process of greater value (Boulkedid et al., 2011). Selection of panel members must also be done using an objective set of “entry criteria” in order to avoid the risk of selection biases. A Delphi study does not require large numbers of participants, as it relies on expert knowledge of selected individuals (Okoli and Pawlowski, 2004). Ten to fifteen experts are recommended for a homogenous group, whereas upto 50 are suggested to be beneficial for a heterogeneous group (Hsu and Sandford, 2007). In the current study, a multi-professional expert panel was chosen to reflect clinical practice with SCI patients. It is hoped that this would make the findings more generalisable to clinical care.

5.1.4 Anonymity

A key feature of the Delphi technique is that participants are anonymous to each other at the point of completing the questionnaire, which allows individual

panellists to express their own opinion without being biased by others in the group (Holey et al., 2007). In specialist clinical fields where experts are likely to know one another, this permits free expression providing rich data for analysis, especially in areas where practices between professional groups are likely to differ (Keeney et al., 2010). Anonymity allows panellists to change opinions without being judged or criticised in public (von der Gracht, 2012). Although this is thought to improve response rates, to achieve a high level of consensus for each round, panellists often need prompting, which requires the researcher to know the identity of each member. This is labelled 'quasi-anonymity' (Hasson et al., 2000, Keeney et al., 2006). In the current study, the lead researcher was aware of the identity of each panel member, allowing comparison of responses across professions and settings.

5.1.5 Controlled feedback

Controlled feedback provides every member of the panel a summary of the group's responses alongside their own at the end of each round (Keeney et al., 2010, Rowe et al., 2005). This can be presented statistically or graphically and allows participants to review the spread of opinion for each statement. This offers an opportunity for participants to reconsider their own responses in light of the group's scores. If their response is in keeping with the group's then their response on the next round is unlikely to change. If their response differs from the group they want to provide an explanation to why their opinion differs, or they may change their opinion in light of anonymised comments. This process aims to increase the convergence of opinions but also understand the reason for lack of consensus (Hsu and Sandford, 2007, von der Gracht, 2012)

5.1.6 Rigour

A criticism of the Delphi technique is the lack of rigour with variations in levels of consensus and subjective analyses (von der Gracht, 2012). The definition of consensus can be dependent on the size and nature of the panel with some studies using an aggregate consensus of 70% or greater (Keeney et al., 2010, Mullen, 2003). The 70% level of consensus has been used in a number of Delphi healthcare studies with mixed panels of experts, recognising that these

may not achieve higher level of group consensus (de Villiers et al., 2005, Watkins et al., 2012, Smith et al., 2012, Hollaar et al., 2016). An objective evaluation of the results uses measures of central tendency (mean, median and mode) and measures of dispersion (standard deviation and interquartile range (IQR)) to summarise group responses and reflect the degree of consensus per statement (Holey et al., 2007, Greatorex and Dexter, 2000). Similarly, Likert scales are often used with the median score being the best measure of group opinion, and IQR reflecting the range (Hsu and Sandford, 2007, von der Gracht, 2012, Clibbens et al., 2012). To reduce the potential for bias, recent studies have employed a representative steering or working group to oversee all stages of the study (Keller et al., 2015, Major et al., 2016). The e-Delphi is a further modification that limits errors or bias in transcribing paper questionnaires, ensuring speed and anonymity of responses (Meshkat et al., 2014).

5.1.7 Study aims

The aim is to achieve consensus on the identification and management of oropharyngeal dysphagia in CSCI using an expert group of multi-disciplinary professionals.

The following research questions were identified:

1. Do experts agree on the risk factors for oropharyngeal dysphagia in CSCI?
2. Is there consensus on the methods of identification and assessment?
3. Can experts agree on what interventions that should be delivered to CSCI patients?

5.2. Method

Three parallel processes took place in the initial stages, firstly, recruitment of a steering group to oversee the Delphi process in terms of appropriacy and reducing bias, secondly, recruitment of the expert panel to provide their expert opinion and thirdly, development of Delphi statements based on the literature and reported current practice. Each aspect of the Delphi was carried out electronically with a plan for up to four rounds, dependent on the consensus achieved in the previous round (Figure 5.1).

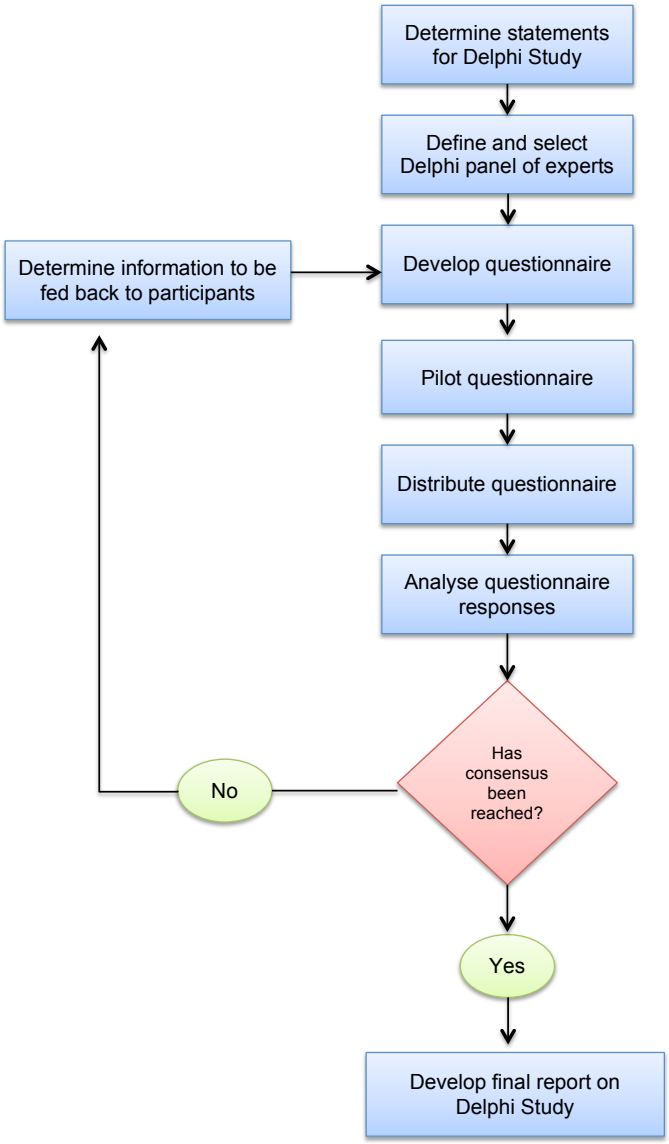

Figure 5.1 e-Delphi study flow chart

5.2.1 Ethics

Local Research and Development approval was received on 06.08.2015 (R&D ID: 15.016) with adherence to Trust and Research Governance Framework (Appendix 2).

5.2.2 Recruitment of steering group

A steering group was set up to ensure content validity of the statements and reduce potential bias by the lead researcher. Eight professionals from the London Spinal Cord Injury Centre were invited by email to join the steering group as each had experience of acute SCI care. Details were provided on the estimated time scale of the study, the role of the steering group and frequency of meetings (Table 5.1). No incentives were offered and participation was voluntary. Consent was obtained via email, with demographic details stored electronically within the Delphi process system. Five of the eight clinical professionals agreed to join the steering group, which comprised of a senior specialist SLT, consultant anaesthetist, anaesthetic fellow, senior physiotherapist and specialist spinal nurse. Information was shared with the group by email before each round of the Delphi, and through face-to-face discussions at the end of each round, to review results and plan the next stage of the process.

Table 5.1 Steering group role and meeting schedule

	Face-to-face meetings	**Electronic correspondence**
Before commencement of Delphi study	Explanation of Delphi study Role of mixed steering group	Consent to join expert panel
Prior to each round of Delphi		Statement review – select to keep, discard or rephrase with comments
After each Delphi round	Review of Delphi results and comments – determine statement modifications or if further round is required	

Members of the steering group were also invited to participate as expert panellists, allowing them to submit their own professional opinion on each statement. Different responses were required for review of statements and

Delphi, which reduced potential for bias, as there were no correct responses, only expressions of opinion for each statement. Before commencing the Delphi the steering group reviewed all statements using an online electronic system to recommend whether to keep, discard or rephrase with free text for comments. These responses were anonymised to allow freedom to comment. Statements were selected based on majority percentage votes. Any with equal votes were reviewed and modified using the comments (Appendix 13) and submitted for round one of the Delphi (Appendix 14).

5.2.3 Recruitment of expert panel

For this study, clinical experts had to be a qualified doctor, nurse, PT, SLT and dietitian with at least 3 years clinical work experience with acute CSCI and experience of managing complex oropharyngeal dysphagia. To recruit a heterogeneous group of clinical experts for the panel, two sampling methods were used: purposive, whereby experts were directly invited by the author; and snowball, whereby experts were asked to invite other colleagues to participate. Those responding to the invitation and fulfilling the criteria of expert, were then taken through a process of consent to participate in up to four rounds of the Delphi and the option of co-authorship. (Appendix 15 and 16).

5.2.4 Electronic Delphi system

Support for the study was provided by The Delphi Process Research Unit (www.dpru.org) (DPRU), a private organisation that carries out commissioned Delphi projects for pharmaceutical and healthcare companies. This gave access to an established online system and expertise to process and analyse the responses. The DPRU on-line system was developed as an electronic questionnaire for on-line completion. This allowed distribution of each round of Delphi statements to each participant, monitoring individual activity and generating response summaries for individuals and the whole group. The DPRU system was set up to send emails to panellists with details of the e-Delphi process, survey links and reminders for completion. Each panellist was provided with their own secure personal log-in and password for access to feedback reports following the completion of each round.

5.2.5 Statement generation

Statements for the e-Delphi were generated from a review of the literature on clinical factors that impact on oropharyngeal dysphagia in CSCI and checked for relevance against the responses from the survey of current clinical practice (chapter 4). Statements were structured with similar opening and closing phrases relating to CSCI patients and oropharyngeal dysphagia. This aimed to limit bias within the wording of each statement and ensure clear interpretation. Following review by the steering group, the statements for the Delphi were arranged with a five-point Likert scale for panellists' ranking. This ranged from disagree strongly (1), disagree (2) neutral (3), agree (4) and agree strongly (5). A free-text comment box was available for additional comments per statement. These were uploaded to the DPRU system in topic, category and statement order (Appendix 14).

5.2.6 Delphi procedure and analysis

Each member of the expert panel was sent details of the study via email with a link to the e-Delphi survey and instructions for completion (Appendix 19). A three-week deadline date was given along with contact details of the DPRU team in event of access issues. An email reminder was sent half way through the three-week deadline to remind panellists to complete the survey. If a panellist had not completed the survey by the deadline, they were contacted directly by email to check whether access issues limited responses. If necessary, the deadline was extended to ensure participation. On completion of each round, panellists were sent both quantitative and qualitative feedback on their own scoring, the group's average scores per statement in addition to group comments (Appendix 17).

At the end of each e-Delphi round, group responses and levels of consensus were analysed by the lead researcher and steering group. This determined which statements would be retained and which required re-submission for the next round. The statements achieving a pre-determined ≥70% cumulative score for disagree strongly and disagree rankings or agree and agree strongly

rankings, were considered to have achieved consensus. Any statements with less than 70% or with a high percentage of neutral rankings were reviewed with the steering group together with any free-text comments for consideration whether to rephrase or discard for the next round. Statements could be rephrased for clarification or discarded if a low level of interest was demonstrated through high neutral scores. The second round consisted of the revised statements and uploaded to DPRU for steering group review of content and construction. The statements for the second round were randomised on the DPRU system to reduce selection bias and ensure judgements were made independent of the first round sequence.

The same analysis took place at the end of the second round, with a sub-level of agreement introduced for statements achieving below 70% group but above 55% ranking. These were given majority agreement status, in light of the heterogeneous nature of the panellists, which may limit achieving 70% consensus. Statements that gained less than 55% ranking were analysed in terms of measures of central tendency and level of dispersion to identify any change in voting between rounds one and two. The median score demonstrated the group opinion and the inter-quartile range (IQR) showed the spread of opinion. Qualitative comments were collated for each statement to qualify responses. The final core items were then selected from all the statements receiving consensus to be included in best practice recommendations. The items receiving majority agreement in the second round were also of significance in the context of the heterogeneous expert panel, and were included in the recommendations, stating that they may need future investigation.

5.3. Results

The study flow diagram (Figure 5.2) shows the stages of the e-Delphi and the processing of the statements by the steering group and expert panellists over two rounds to completion.

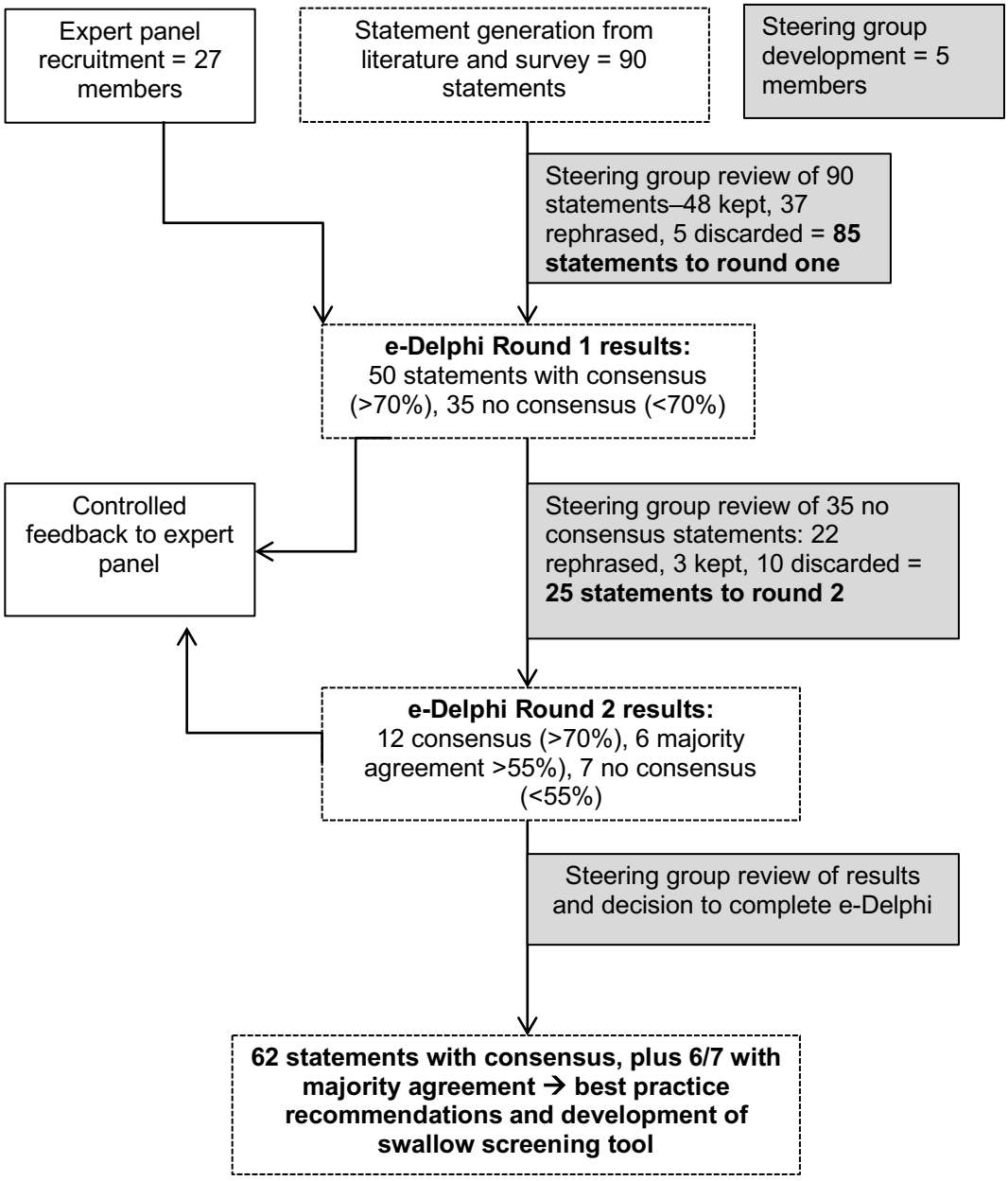

Figure 5.2 Multiple stages in the e-Delphi study

5.3.1 Expert panel demographics

Direct email invitations were sent to 55 named clinicians working in SIUs, members of the UK respiratory SCI network (RISCI) and authors of SCI related studies, based in English-speaking countries, namely Australia, New Zealand, USA and Canada. Information was provided on the details of the study, time commitment and criteria for expert status (Appendix 15). In total, 39 expressions of interest were received, of those, eight did not meet the inclusion criteria. The remaining 31 professionals were invited to consent for up to four rounds of the e-Delphi and submit their demographic information through a secure electronic system (Appendix 16). An additional consent offered the option to co-author a future publication on the study. Consent to be part of the exert panel was received from 27 participants with representation from each professional group (Table 5.2).

Table 5.2 Professional roles of invited and consented panellists

n (%)	Invited n=55	Consented n=27
SLT	22 (40)	8 (29.6)
PT	10 (18.2)	8 (29.6)
Doctor	13 (23.6)	6 (22.2)
Nurse	7 (12.7)	3 (11.1)
Dietitian	3 (5.4)	2 (7.4)

PTs and SLTs were equally represented on the expert panel, followed by doctors, nurses and dietitians (Table 5.3). The majority of the group were female (21, 77.8%), with 3 (11.1%) aged between 25 to 34 years, 12 (44.4%) aged between 35 to 44 years and 12 (44.4%) over the age of 45 years. Experience of working with SCI patients was gained in multiple settings; primarily SIU (24, 88.9%) and ICU (22, 81.5%) with fewer reporting MTC experience (12, 44.4%). Seven (25.9%) selected other environments, such as overseas not-for-profit charity sector (Appendix 18). Overall the group were highly experienced with an average 21.3 working years, and a range of between 6 and 42 years. Experience specifically within SCI averaged 13.2 years with a range of 3 to 29 years. All 27 participants consented to be involved in up to four rounds of the Delphi and 24 (88.9%) agreed to be a co-author on a future publication. In terms of geographical representation 17 (63.0%) panellists

were based in the UK, which included all six doctors, seven PTs, two nurses and two SLTs. Six (22.2%) Australian panellists include two SLTs, two dietitians, one PT and one nurse. Two SLTs were from New Zealand and made up 7.4% of the panellist group, together with SLTs from USA (3.7%) and Ireland (3.7%).

Table 5.3 Demographics of expert panel participants

	n = 27 (%)
Female n (%)	21 (77.8)
Age:	
25-34	3 (11.1)
35-44	12 (44.4)
45-64	11 (40.7)
65+	1 (3.7)
Experience of SCI*:	
SIU	24 (88.9)
ICU	22 (81.5)
MTC	12 (44.4)
Other	7 (25.9)
Years since qualification:	
Mean (SD)	21.3 (9.32)
Range	6-42
Median (IQR)	18 (15-28)
Years working in SCI:	
Mean (SD)	13.2 (8.2)
Range	3-29
Median (IQR)	11 (6-20)
Agreement to co-author	24 (88.9)
Country:	
UK	17 (63.0)
Australia	6 (22.2)
New Zealand	2 (7.4)
USA	1 (3.7)
Ireland	1 (3.7)

* more than one response selected

5.3.2 Final statement selection

Eight topic areas were generated, which contained a number of subcategories from which ninety statements were generated (Table 5.4). The steering group reviewed the 90 statements for content and construction through the DPRU system. Based on majority decision, 48 statements were selected to remain unchanged, 37 were rephrased to change the order of wording, be more specific or correct spelling and five statements were discarded due to being repetitious or irrelevant. For example, only one of the following statements was judged necessary to obtain a consensus on the topic:

1a. If a CSCI patients is under 60 years, they are likely to have swallowing problems

1b. If a CSCI patients is over 60 years, they are likely to have swallowing problems

The statements on gender were not supported by the steering group so these were discarded. As a result, pre- morbid and co-morbid factors were merged and labelled co-morbid. Similarly, oxygen saturation was thought to be unreliable as a clinical indicator in oropharyngeal dysphagia as it can be influenced by other factors, so this statement was discarded.

Table 5.4 Topic areas and sub categories with statement selection by steering group

Topic area pre-steering group	Sub - categories	Original number of statements	Number of statements following Steering group selection
1.Pre-morbid status	age, gender	4	1 (integrated with co-morbid)
2. Co-morbid status	Level, severity, brain injury, cognitive, cervical surgery, respiratory impairment	11	11
3. Definition of dysphagia	Oromotor, laryngeal and pharyngeal, functions	15	15
4. Screening for dysphagia	Oral trials, laryngeal function, respiratory function (tracheostomy and ventilation), position, respiratory measures	17	17
5. Assessment	Diagnostic videofluorscopy, FEES, bedside swallow assessment, position	5	5
6. Identification	Clinical signs: pyrexia, chest infection, suction, aspiration, nutritional measures	7	6
7. Management	Swallowing – NBM, food and fluid options; nutrition – NG, PEG; tracheostomy and ventilation; position – upright, supine, semi-recumbent; oral hygiene, mouthcare; communication	24	23
8. Therapeutic intervention	Communication, swallowing, respiratory	7	7
	TOTAL NO. OF STATEMENTS:	**90**	**85**

5.3.3 Delphi Round One

The first round of the e-Delphi achieved a 100% response rate from the 27 expert panel participants. Out of the 85 statements, 38 (44.7%) achieved 70% consensus of agreement, 12 (14.1%) had a 70% consensus of disagreement, 35 (41.1%) statements that did not achieve a 70% level of consensus. For each topic area, levels of consensus varied (Figure 5.3). Only two statements

achieved 100% consensus, firstly, agreeing that all CSCI patients should be fed via a nasogastric tube if dysphagia is evident, secondly disagreeing that dysphagia in CSCI is a permanent state and unlikely to improve. Statistical summary for round one are listed in Appendix 20.

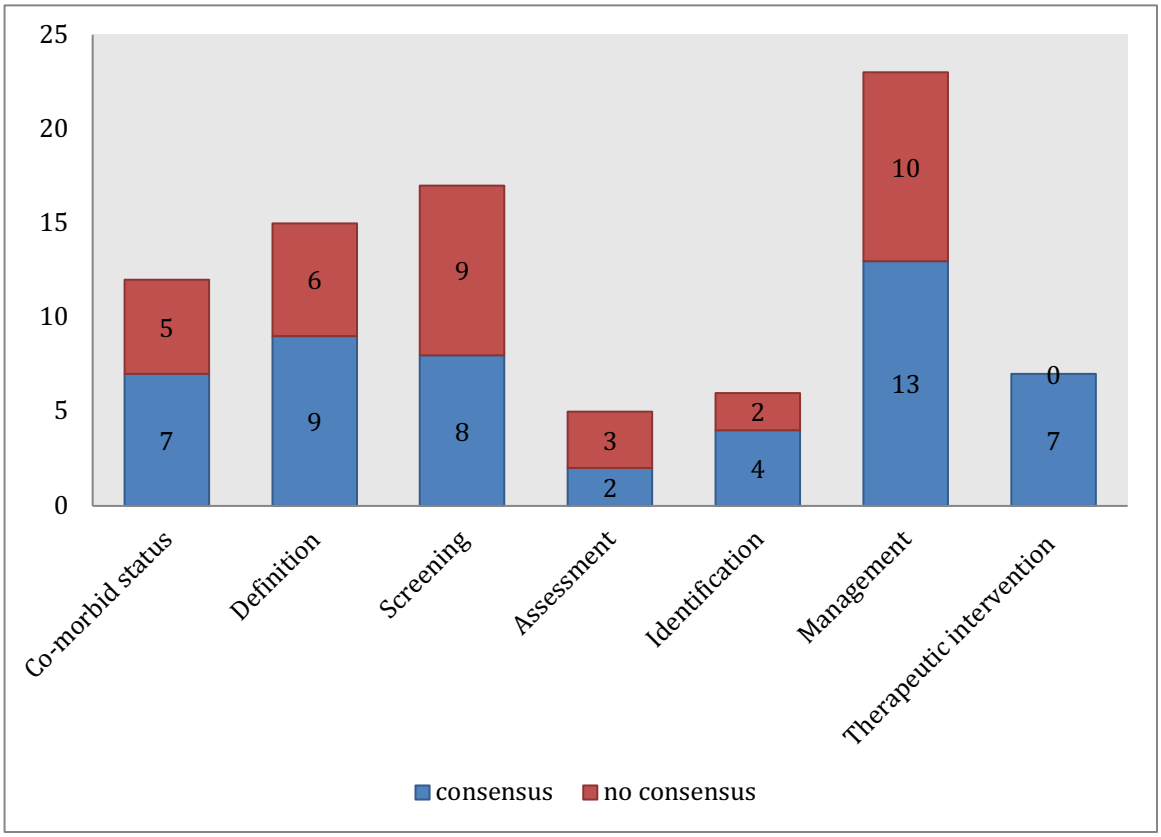

Figure 5.3 Round one statements per topic achieving consensus or no consensus

i. Co morbid factors

There was strong agreement that anterior cervical spine surgery (92.6%), high level CSCI (C1-C4) (92.6%) and associated brain injury (81.5%) contributed to swallowing problems. Respiratory impairment (77.7%) and lower level CSCI (C5-C7) (76.0%) also achieved positive consensus. Statements not achieving consensus were related to older age, severity of injury, thoracic level injury and posterior cervical surgery. These were reviewed by the steering group with reference to panellist's comments. Statements were rephrased for round two (Table 5.5).

Table 5.5 Changes to 'co-morbid status' topic statements from round 1 to round 2

Sub category	Level of consensus	Action	Round 2 statements
Over 60 years	41.4% agree	REPHRASE	Advanced age is not a primary feature in determining dysphagia in CSCI
Thoracic level injury	45% neutral	REPHRASE	A thoracic level injury with respiratory impairment may affect swallowing function
Complete spinal cord injury (AIS A)	62.9% agree	KEEP	If a CSCI patient has a complete spinal cord injury (AIS A) they will require a swallowing assessment
Incomplete spinal cord injury (AIS level B to D)	31.6% neutral	REPHRASE	An incomplete SCI (AIS levels B to D) may have swallowing problems dependent on treatment or surgery
Posterior cervical spinal surgery	47.6% neutral	REPHRASE	If a CSCI patient has posterior cervical spinal surgery, they may experience swallowing problems

ii. Definition

Several statements defining oropharyngeal dysphagia in CSCI generated high group consensus - aspiration of food or fluid (96.3%), reduced laryngeal sensation (92.6%), reduced laryngeal elevation (88.9%), weak cough (88.9%), difficulty of food or fluid transmission from mouth to oesophagus (88.9%), wet sounding voice (77.8%), and absent cough (74.1%). There was high rate of disagreement that facial weakness (85.2%) or lip weakness (77.7%) were features of dysphagia in CSCI. Statements achieving less than 70% consensus were reviewed with the steering group and either rephrased or kept for the second round, based on free-text comments (Table 5.6).

Table 5.6 Changes to 'definition' statements from round 1 to round 2

Sub category	Level of consensus	Action	Round 2 statements
Tongue weakness	51.7% disagree	REPHRASE	CSCI can present with tongue weakness as a secondary feature
Velopharyngeal (soft palate) weakness	37.9% agree	REPHRASE	CSCI can present with velopharyngeal (soft palate) weakness as a secondary feature
Weak voice	63% agree	REPHRASE	CSCI can present with voice weakness as a secondary feature
Coughing after drinking or eating.	66.6% agree	REPHRASE	Dysphagia in CSCI can be characterised by coughing after drinking or eating.
Food or fluid coming out of the tracheostomy tube after eating.	69.3% agree	REPHRASE	Dysphagia in CSCI can be characterised by food or fluid coming out of the tracheostomy tube after eating.
Delayed swallow initiation.	66.7% agree	KEEP	Dysphagia in CSCI can be characterised by delayed swallow initiation.

iii. Screening

The topic of screening achieved consensus for eight out of 17 statements. Risk factors demanding dysphagia screening achieved positive consensus to include deteriorating respiratory function (92.3%), invasive ventilation (84.6%), inflated tracheostomy cuff (81.5%), prolonged intubation (77.8%) and tracheostomy (77.8%). There was consensus to monitor a patient's oral secretion management (85.2%) as well as laryngeal elevation (72.0%) and sensation (72.0%) in order to ascertain the presence of dysphagia. There was 62.9% consensus disagreeing on the use of blue dye. The remaining nine statements did not achieve 70% consensus so were either rephrased or discarded for the next round (Table 5.7).

Table 5.7 Changes to 'screening' statements from round 1 to round 2

Sub category	Level of consensus	Action	Round 2 statements
Non-invasive ventilation	38% disagree	REPHRASE	Non-invasive ventilation may disrupt swallowing function in CSCI patients
Supine for prolonged periods	63% agree	DISCARD	Similar to 48
Oral-motor function	33.3% neutral	REPHRASE	Oral-motor assessment can support an overall impression of dysphagia in CSCI
Voice loudness	36.8% agree	DISCARD	Similar to 17
Swallowing tr ial of water	42.8% agree	REPHRASE	A variety of food trials are useful in the assessment of swallowing in CSCI patients
Swallowing trial of yoghurt	38.1% disagree	DISCARD	Incorporated into 39
Blue dye in food or fluids	62.9% disagree	DISCARD	Incorporated into 39
Forced vital capacity (FVC) below one litre	38.1% disagree	REPHRASE	A sequential fall in FVC is a useful indicator of respiratory impairment affecting swallowing
Forced Expiratory Volume in 1 second (FEV1)	38.1% agree	DISCARD	Incorporated into 43

iv. Assessment

Consensus was achieved for two out of five statements in this topic area. There was strong disagreement that aspiration was the only evidence of dysphagia (92.6%) and disagreement that a clinical bedside swallow assessment was the

best assessment to diagnose dysphagia in CSCI (70.3%). The use of flexible nasendoscopy as best assessment achieved a high level of agreement (66.6%) but no consensus was reached for the use of videofluoroscopy assessment (46.4%) or the requirement to be upright (52.3%). Additional comments acknowledged that whilst videofluoroscopy was considered gold standard, in practice it was a challenge to perform with this patient group. The statements were reviewed by the steering group and discarded or rephrased for the second round (Table 5.8).

Table 5.8 Changes to 'assessment' statements from round 1 to round 2

Sub category	Level of consensus	Action	Round 2 statements
Videofluoroscopy	46.4% agree	DISCARD	Incorporated into 46
Flexible nasendoscopy	66.6% agree	REPHRASE	FEES (flexible endoscopic evaluation of swallowing) is better than videofluoroscopy for the assessment of swallowing in acute CSCI patients
Upright position	52.3% agree	REPHRASE	Where possible, dysphagia is best assessed when the CSCI patient is upright

v. Identification

Out of six statements, consensus was achieved for four - the identification of dysphagia by the presence of food or fluid residue on tracheal suction (88.9%), a chest infection (85.2%), increased oral suction (74.1%) and spiking pyrexia (70.4%), although comments highlighted that these signs may also be due to other causes. The use of serum albumin and pre-albumin received a high number of neutral responses (58.6% and 62.0% respectively) and many panellists responded that they were unsure. In discussion with the steering group, the statement was rephrased for round 2 removing references to specific values instead reflecting the importance of a fall in value (Table 5.9).

Table 5.9 Changes to 'identification' statements from round 1 to round 2

Sub category	Level of consensus	Action	Round 2 statements
Serum albumin value of <3.5g/dl	58.6% neutral	REPHRASE	A sequential fall in serum albumin is an indicator of the impact of dysphagia on nutritional status
Serum pre-albumin level of < 15 mg/ml	62.1% neutral	DISCARD	Incorporated into 54

vi. Management

There were 23 statements of which 13 gained consensus with unanimous consensus for the importance of nasogastric feeding in the presence of dysphagia (100%) and high consensus for transition to gastrostomy for persistent dysphagia (80.7%). There was consensus for the delivery of regular oral hygiene to reduce the risk of VAP (88.4%), moisturising the oral mucosa (85.2%) and an increased risk of dry mouth due to medication (80.0%). There was consensus for disagreement that ventilated patients should remain NBM (80.80%), or ventilator-free in order to eat (85.2%), could not be safely weaned off ventilation (85.2%) or use a speaking valve (81.4%). There was consensus agreement for allowing patients to eat in a semi-recumbent position (74.1%) and 70.4% disagreed that an upright position was required when eating. Panellists' comments highlighted that these decisions were dependent on a patient's condition so were subject to variation. There were ten statements that did not achieve the threshold of 70% consensus. The details of these statements were reviewed alongside the comments submitted. Three statements were merged to try and focus on gaining consensus on the need for NBM status (Table 5.10). Five statements were rephrased in order to increase consensus by simplifying the statements to focus on the theme or reduce the level of the statement claim. One statement was close to 70% consensus, so was re-submitted with no changes and another statement was discarded as consensus had been achieved on a similar theme of talking.

Table 5.10 Changes to 'Management' statements from round 1 to round 2

Sub category	Level of consensus	Action	Round 2 statements
Allowed to eat until evidence of dysphagia	65% disagree	REPHRASE	CSCI patients should be allowed to eat rather than being kept NBM until a definitive swallow assessment is made.
Kept nil by mouth	58.6% agree	DISCARD	Incorporated into 56
Allowed to drink thin fluids.	55.1% disagree	DISCARD	Incorporated into 56
Thickened fluids	65% disagree	REPHRASE	Thickened fluids reduce the risk of aspiration in CSCI patients with dysphagia
Stopped from eating and drinking if coughing	60.7% agree	REPHRASE	Coughing at mealtimes can be suggestive of dysphagia in CSCI patients
Tracheostomy cuff deflated when taking oral intake	69.2% agree	KEEP	Patients with a CSCI should have tracheostomy cuff deflated when taking oral intake to reduce risk of aspiration
Eat when lying in supine	51.7% disagree	REPHRASE	Patients with CSCI should eat and drink in their usual position, which may not be upright.
High risk of ventilator associated pneumonia	58.6% agree	REPHRASE	Regular oral hygiene helps to reduce VAP in CSCI patients
Regular sips of water for dry mouth.	37.9% agree	REPHRASE	Artificial saliva gels rather than fluids should be used to manage dry mouth in CSCI
Use alternative communication	55.1% agree	DISCARD	Consensus reached on talking in statement no.80

vii. Therapeutic intervention

All seven statements in this topic achieved 70% consensus with none requiring submission for round 2. There was unanimous disagreement on the statement claiming that dysphagia in CSCI was a permanent state and unlikely to improve (100%) and dissent that patients should be kept NBM (81.5%) and a tracheostomy cuff remain inflated to prevent aspiration (77.7%). Strong consensus was generated for therapy goals with a focus on a return to normal swallowing function (88.9%), talking (88.9%) and self-ventilation (77.7%), and through daily therapy (80.0%). Submitted comments added that these decisions were dependent on individual patient needs.

viii. Variations between professions

An analysis of the average responses within and across professions, showed that consensus was agreed for most statements (Figure 5.4). Most variance between professions was seen from the dietitians, although their sample was very small. Variations in range of responses were seen within all groups, with a difference of over 2 levels detected within the groups of doctors (2.07), SLTs (2.24) and PTs (2.53) (Appendix 22).

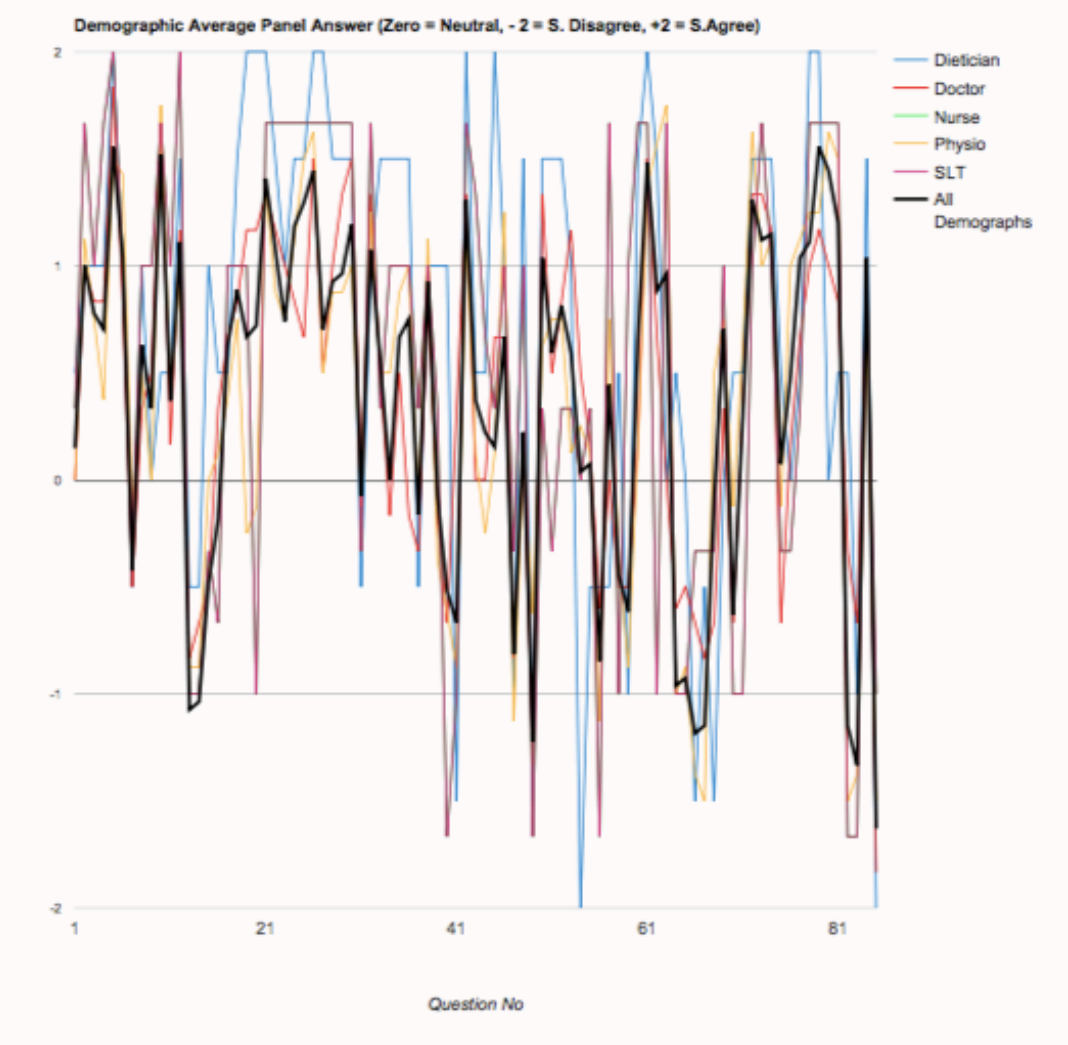

Figure 5.4 Delphi round one average panel answer per statement per professional group

5.3.4 Preparation for Round Two

At the end of round one, the steering group reviewed the results through analysis of the scores and comments. Of the 85 statements, 50 achieving ≥70% group consensus and from the remaining 35 statements three were kept for round two, 10 were discarded as they were considered similar to other

statements or amalgamated into a new statement and 22 were rephrased with the same sub category. This produced 25 statements for the second round. Controlled feedback was provided to each panellist at the end of round one (Appendix 13) with a graphical representation of their individual responses per statement compared to the group average and a summary of round one results.

5.3.5 Delphi Round Two

Twenty-five statements were submitted to the 27 panellists for round two of the Delphi. A 96% response rate was achieved with only one absent response. The six topic areas generated variable levels of consensus (Figure 5.4), with 12 statements out of 25 achieving a consensus level of >70%, a further six (24%) gained a majority agreement of >55% and seven achieved no consensus (Table 5.11). Detailed statistical data can be found in Appendix 18.

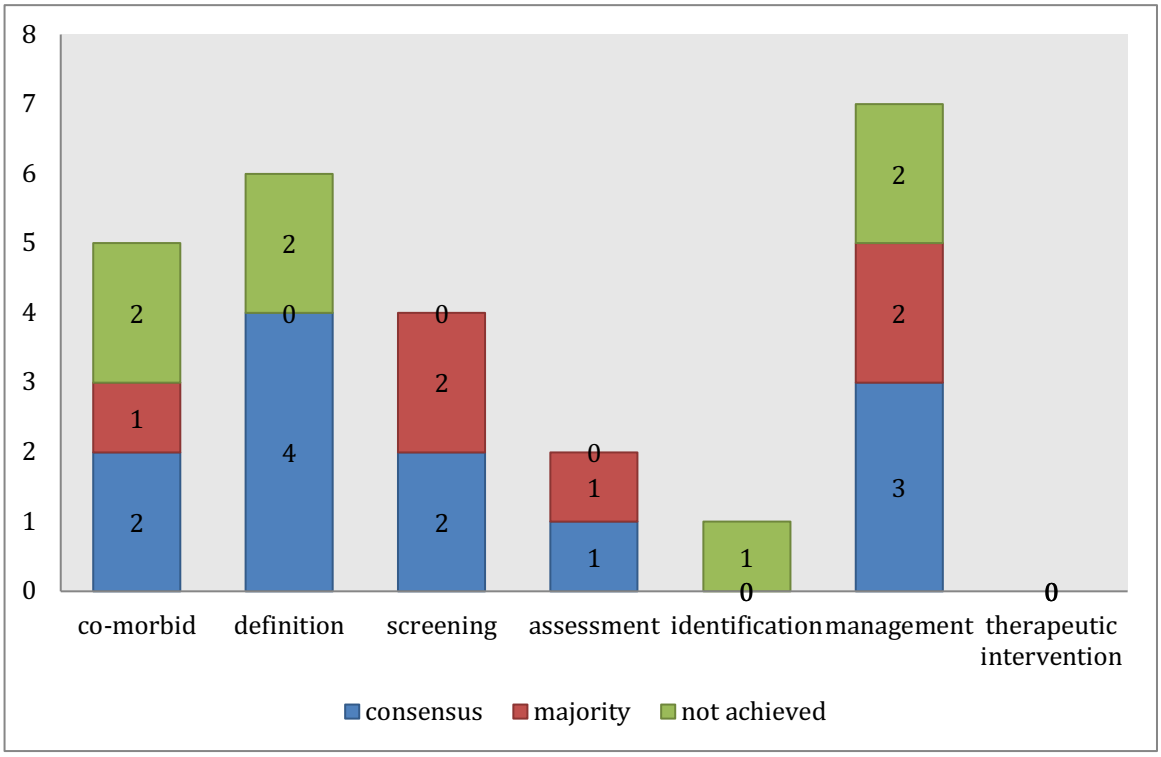

Figure 5.5 Round two topics achieving consensus, majority agreement or no consensus

Table 5.11 Beginning of round two Delphi statements with level of consensus and descriptive statistics

Round 2 statements n=25	**Median (IQR)**	**Mode**	**% consensus**
>70% consensus			
Voice weakness	4 (4-4)	4	100
Incomplete SCI (AIS levels B to D) dependent on treatment or surgery	4 (4-4)	4	100
Oral hygiene helps reduces VAP	5 (4-5)	5	92.3
Variety of food trials for assessment	4 (4-5)	4	88
Coughing at mealtimes	4 (4-5)	4	88.4
Coughing after drinking or eating.	4 (4-4)	4	80.8
Food or fluid from tracheostomy tube	4 (4-5)	4	80.8
Upright position	4 (3.75-4)	4	76.9
Complete spinal cord injury (AIS A)	5 (3.75-5)	5	76.9
Non-invasive ventilation	4 (3.75-4)	4	76.9
Swallow initiation.	4 (3.75-4)	4	76.9
Allowed to eat rather than being kept NBM	2 (2-3)	2	76.9 (disagree)
>55% majority agreement			
Posterior cervical spinal surgery	4 (2.75-4)	4	69.2
Tracheostomy cuff deflated	4 (3-5)	5	68
FEES better than VFS	4 (3-5)	4	65.4
Oral-motor assessment	4 (3-4.25)	4	65.4
Sequential fall in FVC	4 (3-4.25)	4	65.4
Eat and drink in their usual position	4 (3-4)	3	56
No consensus			
tongue weakness	4 (3-4)	4	53.9
Advanced age	4 (2.75-4)	4	53.8
Artificial saliva gels	4 (3-4)	4	53.8
Thickened fluids	2.5 (2-4)	2	50
Thoracic level injury	3.5 (3-4)	4	50
velopharyngeal (soft palate) weakness	3 (3-4)	4	48
Serum albumin	3 (2-4)	3	38.5

IQR = interquartile range
Likert scores: 5=strongly agree, 4=agree, 3=neutral, 2=disagree, 1=strongly disagree

i. Co-morbid factors

For the second Delphi round, five statements were rephrased. Two achieved consensus, one achieved majority agreement and two did not get group consensus. There was unanimous agreement that incomplete SCI may have swallowing problems. On the second round consensus was achieved for complete injuries requiring swallow assessment (76.9%). The impact of

posterior surgery was close to consensus (69.2%) and comments suggested that anterior surgery had greater clinical impact on dysphagia. Statements on advanced age and thoracic level injury failed to reach consensus.

ii. Definition

Out of six statements, four gained consensus and two achieved no consensus. There was unanimous consensus that a weak voice was a secondary feature (100%) and strong consensus that coughing with oral intake (80.8%), food leaking from tracheostomy (80.8%) and delayed swallowing (76.9%) were qualities of dysphagia. Tongue weakness (53.9%) and velopharyngeal weakness (48%) failed to achieve consensus and comments suggested that these were related to cranial nerve impairment not impairment of the spinal nerves.

iii. Screening

Out of four statements two achieved consensus that a variety of food trials are useful in assessing swallowing (88.0%) and non-invasive ventilation could disrupt normal swallowing (76.9%). There was majority agreement for statements supporting the use of oromotor assessment (65.4%) and monitoring deteriorating FVC (65.4%).

iv. Assessment

There were two statements in round 2, with one achieving consensus that the patient's swallowing should be assessed in an upright position where possible (76.9%) and one with majority agreement that the use of FEES is better than VFS for CSCI patients (65.4%).

v. Identification

Only one statement was submitted under this topic heading. The use of serum albumin levels was not supported as a clinical measure of nutritional compromise and associated dysphagia achieving only 38.5% consensus. Comments suggested that these levels may be affected by other medical problems and that patients should be provided with alternative nutrition to prevent signs of malnutrition.

vi. Management

Out of seven statements three gained consensus. There was consensus disagreeing that patients should be allowed to eat before a swallow assessment (76.9%). There was strong consensus on the importance of regular oral hygiene to reduce VAP (92.3%) and that coughing at meals was suggestive of dysphagia (88.4%). The use of tracheostomy cuff deflation for eating (68%) achieved majority agreement alongside the suggestions that CSCI remain in their usual position to eat and drink (56%). No consensus was achieved on the use of thickened fluids (50%) or artificial saliva to relieve dry mouth (53.8%).

vii. Variations between professions

In the second round of the Delphi, the greatest variance between the groups was shown by dietitians and SLT (Figure 5.6). A variance of more than two within groups was seen amongst PTs (2.24) and SLT (2.2) (Appendix 25).

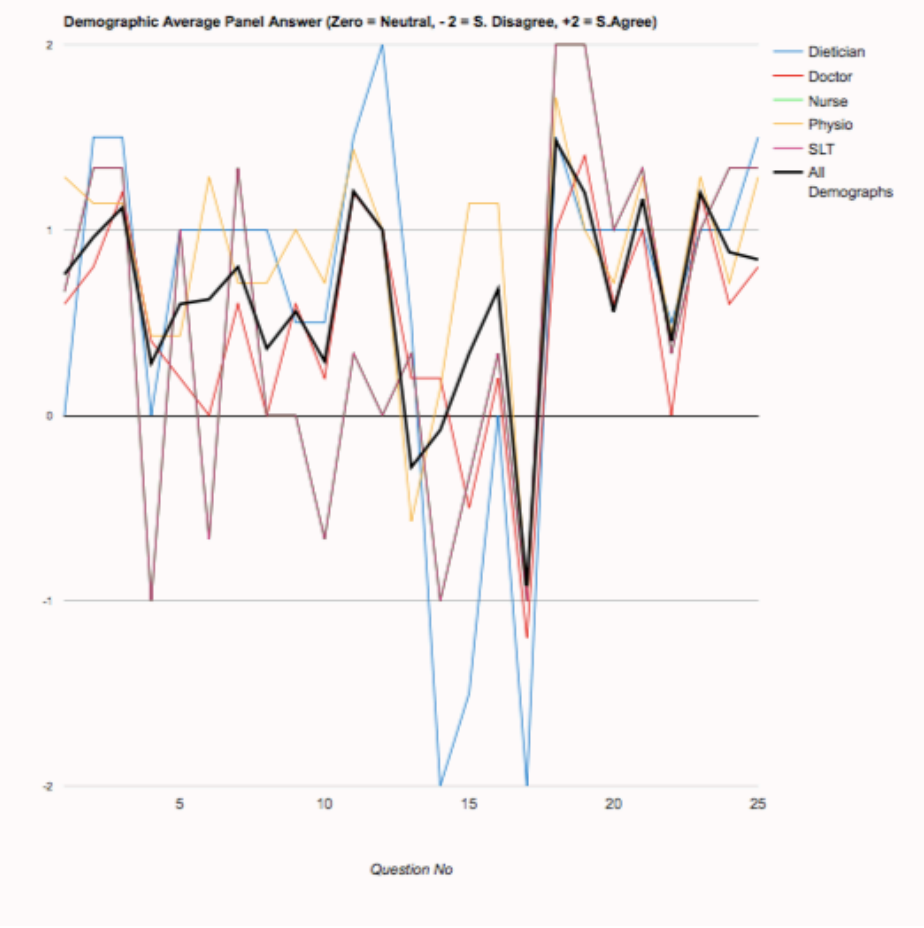

Figure 5.6 Delphi round two average panel answer per statement per professional group

5.3.6 Descriptive statistics

Out of 25 statements sent to the expert panel in round two, 12 statements achieved group consensus of ≥70%. For the remaining 13 statements without consensus, analysis of summary statistics demonstrated a change in rankings between rounds one and two (Table 5.12). A change in mean scores is observed for all statements except serum albumin with an increasing value taking them past neutral (3) towards agree (4), suggesting a modification to panellists responses. The median scores for other statements demonstrate a move towards agreement. The mode also shows a shift towards agreement with 46% changing by one level and two statements (15%) changing by two levels.

Table 5.12 End of round two non-consensus statements descriptive statistics

sub category	Mean		Median (IQR)		Mode		Consensus
	R1	R2	R1	R2	R1	R2	
>55% majority agreement							
Posterior cervical spinal surgery	3.33	3.54	3(3-4)	4(2.75-4)	3	4	69.2%
Tracheostomy cuff deflation	3.69	3.8	4(2.75-5)	4(3-5)	5	5	68%
FEES	3.63	3.81	4(3-4)	4(3-5)	4	4	65.4%
Oral-motor assessment	3.12	3.65	3(2-4)	4(3-4.25)	4	4	65.4%
FVC	3.33	3.81	3(2-4)	4(3-4.25)	2	4	65.4%
Eat/drink in usual position	2.44	3.44	2(2-3)	4(3-4)	2	3	56%
No consensus							
Tongue weakness	2.59	3.46	2(2-4)	4(3-4)	2	4	53.9%
Artificial saliva	3.15	3.58	3(2-4)	4(3-4)	3	4	53.8%
Advanced age	3.19	3.31	3(2-4)	3.5(2.75-4)	3	4	50%
Thickened fluids	2.35	2.81	2(1.75-3)	2.5(2-4)	2	2	50%
Thoracic level injury	2.62	3.38	3(2-3)	3.5(3-4)	3	4	50%
Velopharyngeal weakness	2.89	3.4	3(2-4)	3(3-4)	3	4	48%
Serum albumin	3.04	2.96	3(3-3)	3(2-4)	3	3	37% (neutral)

R1= round one, R2 = round two, IQR = interquartile range
Likert scores: 5=strongly agree, 4=agree, 3=neutral, 2=disagree, 1=strongly disagree

The levels of consensus and descriptive statistics were reviewed with the steering group at the end of round two. After reviewing the scores and comments it was agreed that further changes in ranking were unlikely to be elicited for the remaining non-consensus statements in another round. This formed the decisions to end the Delphi after two rounds. Members of the expert panel were sent a summary report (Appendix 24).

5.3.7 Delphi results summary

At the end of the two-round e-Delphi process, 62 of the original 85 statements had achieved ≥70% group consensus and a further six achieved majority agreement from a heterogeneous expert panel, summarised in Table 5.13. Seven statements did not achieve group consensus at the end of round two with the mean scores show neutral ranking, although the modes reveal a move towards agreement for five of these statements. This suggests an influence of the feedback given to each panellist after round one on the subsequent response selections for round two.

Table 5.13 Delphi topics and sub category items achieving consensus, majority agreement or non-consensus after two Delphi rounds

Topic	≥ 70% consensus	majority agreement (≥55%)	No consensus after round one and two
Comorbid factors	Brain injury/cognitive impairment* C1-C7/Tetraplegia* Anterior cervical spine surgery Complete injury (AIS A) Incomplete injury (AIS levels B-D) only with additional features Respiratory impairment	Posterior cervical surgery	Thoracic level injury Advanced age
Definition	Impaired laryngeal sensation Difficulty of food/fluid transmission to oesophagus Reduced laryngeal elevation Ineffective/absent cough* Voice weakness Wet voice Food/fluid aspirated into lungs Coughing after oral intake Food or fluid from tracheostomy tube Delayed swallow initiation (-) Facial weakness		Velopharyngeal weakness Tongue weakness
Screening	Deteriorating respiratory function Tracheostomy Prolonged intubation Oral secretion management Invasive ventilation Non-invasive ventilation Tracheostomy cuff inflation Observe laryngeal elevation Variety of food trials	Oromotor assessment Sequential fall in FVC (-) Blue dye	(-) Yoghurt
Assessment	Upright for assessment (-) Aspiration as only sign (-) Clinical bedside evaluation	FEES	Videoflouroscopy
Identification	Chest infection Spiking pyrexia Increased oral suction		Serum albumin

Management	Keep NBM until swallow assessment NG feeding and transition to PEG at 4-6 weeks* Keep NBM if paralytic ileus Regular oral hygiene and moisturisation* Dry mouth Coughing Use own voice Use semi-recumbent position (-) Only eat in upright (-) Do not use speaking valves (-) Inability to wean (-) Only feed when off ventilation (-) Do not eat if ventilated	Tracheostomy cuff deflation Usual position, not upright	Thickened fluids Artificial saliva gels Drink thin fluids
Therapeutic intervention	Aim for return to safe oral intake Aim to achieve verbal communication Aim for self-ventilation Daily swallow therapy (-) Permanent state and unlikely to improve (-) Remain NBM (-) Keep cuff inflated		

*more than one statement included
(-) indicates negative consensus

5.4. Discussion

Much of the literature relating to oropharyngeal dysphagia in CSCI has attempted to classify the risk factors, in order to direct early identification (Shem et al., 2012a, Brady et al., 2004). Although the evidence suggests impact from tracheostomy, ventilation and surgery, clear clinical guidance has not been developed for use in the general clinical environment. As a result varied practices have been reported in both specialised and non-specialised units (Chapter 3). To better inform clinical practice in the identification and management of oropharyngeal dysphagia, a Delphi approach was used to capture expert opinion. This will help to establish agreed clinical approaches and develop best practice recommendations for staff across care settings.

In this Delphi study, the expert panel was multidisciplinary to emulate the wide team involvement for CSCI and oropharyngeal dysphagia in the acute clinical setting. The panel achieved consensus on 62 (73%) of 85 statements delivered over two rounds, which provides strong direction for clinical recommendations. Although there were some variations in opinions between professional groups, the Delphi considers levels of consensus as a cohort, especially as it applies to clinical practice delivered as a multi-disciplinary team. Areas of disagreement and clinical certainty were identified especially for screening, assessment and management of oropharyngeal dysphagia and associated complications.

5.4.1 The nature of oropharyngeal dysphagia in CSCI

There was a high level of consensus across professionals on the definition and signs of oropharyngeal dysphagia in CSCI. This allows differentiation from oropharyngeal dysphagia in other conditions, especially stroke, excluding signs of cranial nerve involvement. The agreed focus is on laryngeal and pharyngeal dysfunction as described in the literature (Wolf and Meiners, 2003, Shem et al., 2012b, Shin et al., 2011). Although a cough is routinely used to evaluate the presence of oropharyngeal dysphagia, experts agreed in CSCI a weak or absent cough is a key feature, making it an unreliable clinical sign of aspiration. This should direct clinicians away from existing bedside assessments that rely on presence of cranial nerve signs and cough to determine oropharyngeal dysphagia (O'Horo et al., 2015).

5.4.2 Methods of identifying oropharyngeal dysphagia in CSCI

The Delphi process helped achieve expert consensus on the multiple factors that contribute to oropharyngeal dysphagia in CSCI. Co-morbid factors included brain injury, cervical level injury, high severity injury (AIS A) injury, anterior cervical spine surgery and respiratory impairment, as previously detailed in the literature (Abel et al., 2004, Brady et al., 2004, Chaw et al., 2012, Chen et al., 2012). Age, which has often been reported as a significant factor (Kirshblum et al., 1999, Shin et al., 2011, Shem et al., 2012a), only achieved majority agreement from the exert panel. Although posterior surgery, lower cervical injury and incomplete injury were not found to have direct impact on oropharyngeal dysphagia, they were considered contributory factors when present in conjunction with additional treatment or surgery. This supports the findings of studies that report oropharyngeal dysphagia following elective cervical spine surgery in those without traumatic injuries (Smith-Hammond et al., 2004, Radcliff et al., 2013, Shin et al., 2011), so this is likely to be an added complication for those with CSCI who also require surgery to stabilise bony fractures of the cervical spine.

Variations in consensus on screening methods reflected differences in clinical practice between the experts. Experts disagreed on the use of yoghurt and blue dye water for screening, although this did not achieve consensus. The use of a variety of food textures during screening was supported in round two. This suggests a move away from water-only testing, which is a common component of oropharyngeal dysphagia screening tools (Cichero et al., 2009, Speyer, 2013, Suiter and Leder, 2008), towards trials of food textures. Little is known about optimum textures for CSCI patients, although a recent case study reported that CSCI patients may perform better with cohesive textures (Morgan and McRae, 2016).

In attempting to better identify the presence of oropharyngeal dysphagia, clinical experts disagreed with the use of clinical bedside evaluation and aspiration as the only sign of impairment. Associated with this is the use of blue dye, which achieved greater dissent for screening for oropharyngeal dysphagia, in line with studies demonstrating its poor sensitivity for tracheostomy patients (Brady et al., 2015). These results support the need for in-depth assessment of

swallow dysfunction focussing on pharyngeal impairments (Stokely et al., 2015, Neubauer et al., 2016). This would require evaluation with instrumental assessments, FEES or VFS, however neither achieved consensus. FEES gained majority agreement whilst VFS was reported to be challenging to access for acute CSCI patients.

5.4.3 Intervention

There is very little evidence available on effective clinical management of oropharyngeal dysphagia in CSCI and optimum interventions (Valenzano et al., 2016). The Delphi attempted to gain consensus on some of the contentious issues including patient position for oral intake, thickened fluids, non-oral enteral feeding, NBM status and tracheostomy cuff status, highlighted as mixed practices in the survey study (Chapter 3).

Consensus from the Delphi supported the assessment of patients in upright although eating could take place in a non-upright position, which acknowledges the challenges for CSCI patients. This contrasts with a long-standing SLT requirement fro patients to be fed in upright in the belief that this provides better airway protection and hence less risk of aspiration (Groher and Crary, 2015). This may leave CSCI patients being refused oral intake if they need to be semi-recumbent or supine. A number of studies have looked at swallowing in different positions in healthy individuals and found that supine or semi-supine position are not detrimental and can offer further protection by directing fluids towards the pharyngeal wall rather than towards the airway (Barkmeier et al., 2002, Sakuma and Kida, 2010, Su et al., 2015). This would support earlier opportunities for commencing swallowing trials.

A common intervention that did not gain consensus was the use of thickened fluids, which is used to reduce the risk of aspiration, as reported in the results of the survey study (chapter 3). Although commonly used with oropharyngeal dysphagia following stroke, traumatic brain injury and neurodegenerative disorders fluids (Groher, 1987) its use with CSCI patients has not been demonstrated. With ineffective pharyngeal clearance described as the main impairment (Ward and Morgan, 2009, Brady et al., 2004, Shem et al., 2012a)

thickened fluids may be more liable to remain in the pharynx, leading to delayed aspiration (Cichero, 2013). A recent review reported weak evidence to support the use in those with oropharyngeal dysphagia, demanding further research (Andersen et al., 2013).

There was unanimous agreement from the expert panel that NG feeding was essential for dysphagic patients, and consensus to transition to PEG if problems persisted. This supports recommendations in the literature (Thibault-Halman et al., 2011) although clinical practice is known to vary with increased reports of malnutrition in those admitted to SIUs (Wong et al., 2012a). Consensus also supported the premise that oropharyngeal dysphagia in CSCI patients is likely to improve and benefits from daily swallow therapy. Only one longitudinal study has reported on the outcomes of swallow therapy, with only one out of 41 patients dependent on tube feeding (Wolf and Meiners, 2003). This contrasts with the experience of participants in the interview study (Chapter 4) who were given little or no intervention and terminal prognoses for recovery from oropharyngeal dysphagia.

There was majority agreement that CSCI patients should eat with the tracheostomy cuff deflated. Clinically, this is a contentious issue with mixed practices reported in the survey study (chapter 3). The evidence is mixed as the cuff is thought to protect from aspiration of saliva but protection from food aspiration has not been verified (Ding and Logemann, 2005). Recent studies report a preference for cuff up eating especially for ventilator dependent patients (Mullender et al., 2014, Pryor et al., 2016a, Ledlie and Cobby, 2014). Cuff deflation permits expiratory airflow, which benefits laryngeal functions necessary for cough, swallowing and verbal communication (Morgan and McRae, 2015, Cameron et al., 2009). These functions also offer to improve the quality of life of CSCI patients, as stated by participants in the interview study (Chapter 4).

5.4.4 Limitations

A key criticism of the Delphi is its variations in methodology for consensus levels, panel sizes and Likert scales. In this Delphi the consensus level was set at 70% to allow for an achievable level of agreement amongst a heterogeneous

group of experts, both in terms of profession and geography. A mixed group is less likely to achieve high consensus due to their own differences in practice, so lower levels of consensus have been deemed acceptable (Keeney et al., 2010) depending on research aims and panel size. Majority agreement of 55% and over in the second Delphi round was used to capture changes of opinion where 70% consensus could not be achieved.

One of the limitations was the requirement of the expert panel to be clinical experts rather than academic experts, which may that they may not have been familiar with the most recent evidence in the field of dysphagia management. Also the uneven spread of professions on the expert panel may have influenced the results, however heterogeneity of opinions can contribute to improved response rate and richer data in a Delphi study (Boulkedid et al., 2011). With few SCI experts in the UK, international clinical experts were sought, providing a broader range of experience. The recruitment of both nurses and dietitians was a challenge with reasons for refusal given as not considering themselves experts, not working solely in SCI or unsure of oropharyngeal dysphagia management. Although there was greater representation of PTs and SLTs, these groups were heterogeneous in their experience and had the appropriate level of expertise to participate in the Delphi.

In this Delphi study, the topic areas and statements were generated in advance based on the literature and survey results. This may be considered as a limitation as it may restrict opinions and bias responses. An alternative version of the Delphi seeks topics of uncertainty from the expert panel that are then ranked on subsequent rounds (Hasson et al., 2000). Although the statements were pre-determined, bias was limited through use of a steering group to oversee content and experts were able to express further opinions through the free-text facility.

A further limitation of the Delphi is the variation and absence of consensus for a number of statements. This does indicate a lack of importance but that there is insufficient knowledge or awareness for an opinion to be made. This emphasises the need for further studies investigating these aspects. Statements with consensus do not suggest that this is a correct response but

merely the most agreed response by a group of experts who have a higher level of knowledge in this area. It cannot be presumed that experts will agree on statements and the iterative Delphi process is designed to influence opinions through controlled feedback and anonymity (von der Gracht, 2012). This allows participants to change opinions without losing credibility, especially when considering areas where little evidence exists.

5.5. Conclusion

The Delphi study has demonstrated the value in collating international expert opinion and knowledge in the management of oropharyngeal dysphagia in CSCI, in the absence of cohesive evidence. A level of consensus was achieved on the majority of topic areas, although gaps in knowledge remain. Although consensus offers agreement rather than a correct approach, best-practice recommendations based on these can support the care of CSCI patients in different acute care settings. This information can also be used a baseline against which to gather evidence to either support or refute the consensus statements.

Using the identified risk factors, a oropharyngeal dysphagia screening tool can be constructed for use by multi-professional staff to facilitate early identification of risks for oropharyngeal dysphagia. The next study will develop and evaluate usability of the screening tool to evaluate the impact on staff clinical decision-making.

6. Study 4: Development of a swallow risk screening tool for CSCI and feasibility study of its use in two major trauma centres

6.1. Introduction

The previous survey (chapter 3) and interview (chapter 4) studies identified variations in clinical practice for staff managing CSCI patients with oropharyngeal dysphagia. The survey study reported differences in clinical approaches across specialised and non-specialised units and also between professionals in each of those units. This suggests limited knowledge about the presentation of oropharyngeal dysphagia in CSCI and the interventions required. The participant interviews provided insight into the experiences of patients and variable staff decision-making on eating, drinking, communication options and rehabilitation. These left participants feeling confused and distressed. With a lack of clinical guidance, the Delphi study (chapter 5) generated expert consensus on the key risk factors for oropharyngeal dysphagia, optimum methods for screening and clinical management. This information contributes to best-practice recommendations.

The literature detailing oropharyngeal dysphagia in CSCI agrees that early screening is beneficial to prevent complications that not only impact on respiratory function but also nutrition, oral hygiene and verbal communication, especially for ventilator dependent patients (Shem et al., 2012a, Kirshblum et al., 1999). A CSCI-specific swallow screening tool has not been proposed. Current swallow screening tools have focussed on stroke patients and do not adequately identify pharyngeal and laryngeal impairments, which are a key feature in CSCI, and vary in their sensitivity to detect aspiration (O'Horo et al., 2015, Daniels et al., 2012, Brodsky et al., 2016). The standard methods of assessment often require trials of oral intake at bedside, using overt signs such as coughing to indicate aspiration and oropharyngeal dysphagia. In CSCI patients who have weak or absent cough, signs of oropharyngeal dysphagia may be absent and lead to a decision to commence oral intake. This puts patients at high risk of complications that only become apparent with the

development of respiratory symptoms, such as chest infections (Shem et al., 2012a). The ideal screening tool would identify risk factors for oropharyngeal dysphagia in CSCI by employing a checklist, that would highlight those requiring further instrumental assessment of pharyngeal function to determine optimal interventions based on the outcome (Speyer, 2013).

Critical care is a demanding environment delivering complex care to vulnerable patients. Admission numbers of CSCI patients are often small, with referrals from one MTC averaging ten a month (personal communication from Spinal outreach team, 20th May 2016). As these patients often have extended stays in the ICU, it is valuable to consider this environment and staff roles. Nursing care is usually provided on a ratio of 1:1 with doctors performing daily ward rounds, PTs delivering regular respiratory interventions to reduce the risk of atelectasis. The roles of the SLT and dietitians are often peripatetic and delivered only to specific patients that are referred to them. This relies on the clinical decision-making by the other members of the team who use their judgment to estimate if there are difficulties with swallowing.

There is a lack of evidence on how staff make the decisions about the presence of oropharyngeal dysphagia. In the survey study (chapter 3), staff reported referring to SLT following signs of oropharyngeal dysphagia on swallow screening. A wide range of screening methods were reported including use of blue dye, thickened fluids, saliva, water and yoghurt, demonstrating no standard swallow screening process. This increases the risk of inaccurate screening and poor identification of oropharyngeal dysphagia. CSCI patients require a swallow screening tool that is easily understood and accessible to all staff members and reduces the risk of developing aspiration. The Delphi expert panel generated consensus on the key risk factors that contribute to oropharyngeal dysphagia in CSCI. This chapter will detail the development of a screening tool based on those results. To evaluate the tool's usability with multi-disciplinary staff in a general critical care environment, a feasibility study was planned.

6.2. Background

CSCI is a complex acute condition with primary admission to a major trauma centre, requiring multi-disciplinary input in order to prevent life-threatening

complications. National guidance for the initial management of people with SCI (CRG for Spinal Cord Injury, 2016) provides a checklist of clinical areas requiring protocolisation. Priority is given to life-preserving acute interventions, specifically surgery and ventilation, however oropharyngeal dysphagia is not included despite being a key risk factor for respiratory complications and pneumonia (Abel et al., 2004, Chaw et al., 2012, Shem et al., 2012a). This leads to prolonged ICU stays and increased need for interventions. Studies have demonstrated that health gains can be achieved through a programme of early infection prevention, helping to improve short and long-term neurological outcomes (Failli et al., 2012, Kopp et al., 2017). Early oropharyngeal dysphagia identification can reduce complications and improve outcomes and has been a recommendation of a number of studies (Seidl et al., 2010a, Shin et al., 2011, Kirshblum et al., 1999). Despite this there is no reliable non-invasive method to screen, despite a number of clinical pathways having been established (chapter 3). It is valuable to explore existing clinical pathways and oropharyngeal dysphagia screening processes in order to appreciate the challenges.

6.2.1 Clinical pathways in SCI care

Clinical pathways exist to guide staff on optimum care in order to minimise complications and ensure standard, consistent practices. In CSCI, a number of pathways have been developed to guide specific approaches to care, such as for bowel management (Multidisciplinary Association of Spinal Cord Injured Professionals, 2012), neuropathic pain (Multidisciplinary Association of Spinal Cord Injured Professionals, 2008) and respiratory weaning (Respiratory Information for Spinal Cord Injury, 2012). These are accessible to staff across specialised and non-specialised units to ensure equity of care. No pathways exist for the management of oropharyngeal dysphagia in CSCI despite being associated with poor outcomes (Chaw et al., 2012, Bradley et al., 2011). Although coughing and choking are expected symptoms of oropharyngeal dysphagia, silent aspiration is a common feature that cannot be detected on bedside evaluation (Shin et al., 2011). For this reason, a reliable screening tool is required to identify occult oropharyngeal dysphagia as a first step in the pathway.

A related clinical pathway is nutritional management, which can be detrimentally affected by oropharyngeal dysphagia. The malnutrition screen tool, MUST is now established in many acute clinical settings (British Association of Parenteral and Enteral Nutrition, 2003) designed to identify risk of malnutrition. Despite the availability of MUST, the Spinal Nutrition Screening Tool (SNST) was developed as a SCI-specific malnutrition screening tool (Wong et al., 2012b) after identifying a high prevalence of malnutrition in SCI patients admitted to SIUs (Wong et al., 2012a). The SNST showed greater sensitivity for malnutrition in SCI patients when compared to the non-specific nutrition tool (MUST). SCI levels C1 to C8, ventilation requirement and nil by mouth status were identified as high risk factors. This highlights the need for a spinal specific tool that identifies the specific impairments in this population. However, Wong's study on malnutrition rates (Wong et al., 2012a) only represented admissions to half of UK SIUs and provided no data on the nutritional status of SCI patients remaining in non-specialised units.

Guidance from RISCI (2012) is made available to staff in non-specialised units as part of the outreach service, to support weaning and respiratory care. This guidance presumes a level of experience and is used in conjunction with patient-specific advice. With regards to swallow management it recommends advice be sought from the local SLT.

6.2.2 Oropharyngeal dysphagia screening tools

A variety of methods have been employed to screen for oropharyngeal dysphagia symptoms and signs to minimise risk and complications. There are screening questionnaires, which act as checklists of reported symptoms and screening examinations which require administration of a test or procedure in order to identify a specific outcome. The former can be patient-reported or completed by a clinician, whereas examinations must be done by specialists, ideally an SLT.

i. Screening questionnaires

An increasing number of patient-reported questionnaires have been created for specific and general oropharyngeal dysphagia conditions (Patel et al., 2017). These tend to be for stable oropharyngeal dysphagia with the aim of providing

insight into impact through subjective reports. None are specified for CSCI and although some are specifically for use with cervical spine surgery patients (Skeppholm et al., 2012, Bazaz et al., 2002, Siska et al., 2011), they are designed to capture pre or post-operative changes in elective cases.

Swallow screening tools for use by clinicians include those designed for nurses or non-SLT staff to administer, particularly for stroke patients. These aim to train nurses to identify signs or problems requiring further specialist assessment or to allow those with no signs to proceed with oral diet. The Gugging Swallowing Screen (GUSS) was developed for use by trained stroke nurses or therapists (Trapl et al., 2007) and required them to administer a preliminary assessment followed by a direct swallowing test, using a total scoring system to determine if further formal investigations are required. High inter-rater reliability was attained, although this was only for stroke patients with clear signs of aspiration such as coughing, voice change and drooling. Similarly the Toronto Bedside Swallowing Screening Test (TOR-BSST) (Martino et al., 2009) used trained nursing staff to screen for risk of oropharyngeal dysphagia in stroke patients before any symptoms developed. They did this through identification of 5 items, namely voice quality before and after screening, water swallow test, pharyngeal sensation and tongue movement. Although it achieved high validity and sensitivity, the validation study excluded patients with respiratory compromise and head and neck surgery. Edmiaston et al. (2010) specifically developed the Acute Stroke Dysphagia Screen (ASDS) that could be used by non-SLTs with minimal training to identify swallowing problems in stroke patients. This relied on confirmation of presence or absence of facial, tongue or palatal symmetry and a water swallowing test, checking for any abnormal responses. This streamlined the swallow screen pathway by reducing the need for specialist assessment for those without swallowing allowing them to resume oral intake.

The value in triaging a mix of dysphagia patients through nurse screening was evidenced in a study highlighting the discrepancy between SLTs weekly working hours and 24 hour provision of care by nurses (Cichero et al., 2009). This made it necessary for nurses to, play an important role in early recognition of oropharyngeal dysphagia. Nurses were given a 30-minute training session to identify potential risk using a checklist of diagnostic categories. If any of these

were present, a further interview with the patient or family would ascertain any clinical symptoms, followed by a further checklist of signs and water swallow test. Cichero's study (2009) was applied to a mixed patient caseload with high reported sensitivity and specificity. In a retrospective study comparing nurse-performed screening to no screening for post-extubation patients in critical care, See et al. (2016) reported an increase in patients' commencing oral feeding with a corresponding reduction in pneumonia and length of stay. Nurses had a 3-hour training session before being allowed to administer a water swallow test and observed for signs of aspiration, specifically choking or gurgling. If no signs were evident, oral intake could be commenced. These studies demonstrate the value in training non-SLTs to screen for swallowing problems, although they rely on the presence of overt signs. For CSCI patients with a high incidence of silent aspiration, a swallow screen has to be sensitive to their impairments, to prevent the development of respiratory complications.

ii. Screening examinations

Most swallowing screens attempt to identify the presence of aspiration, to highlight risk, usually through swallow trials with food or fluids using cough or change in voice quality as an endpoint (Brodsky et al., 2016). A number of systematic reviews of bedside screening assessments have reported studies with mixed methodologies predominantly with stroke or neurological patients and poor sensitivity and specificity for identifying risk of oropharyngeal dysphagia (Bours et al., 2009, Speyer, 2013, O'Horo et al., 2015, Kertscher et al., 2014). None of the screening methods were sensitive to identifying silent aspiration, making them difficult to generalise to the CSCI population (Shin et al., 2011).

Cough Reflex Testing has been proposed as an effective screening tool for detecting laryngeal sensitivity through inhalation of nebulised citric acid, which acts as an irritant to the mechano and chemoreceptors in the larynx. Wakasugi (2008) considered cough reflex testing as an effective screening method for silent aspiration in a mixed population. Inhaled citric acid was used to elicit a cough followed by a water swallow test (WST), which was then validated by either VFS or FEES. Although the group was heterogeneous, patients with severe swallowing problems were excluded, which may have biased the results.

Although the WST had been reported as an effective screen in a wide range of patients (Wakasugi et al., 2008), a later study (Suiter and Leder, 2008) excluded tracheostomy and ventilated patients with a high risk of silent aspiration due to poor sensitivity.

Overall, the reliability of screening tools for detecting silent aspiration is poor increasing the risk of complications following oral trials. For this reason, a SCI-specific screening tool was required based on expert consensus, with particular applicability for staff in non-specialised units. Its usability is dependent on consistent staff adherence to guidance in their clinical settings. To assess the feasibility of using a spinal-specific swallow screening tool as part of existing standard care, a pragmatic observational study was required in non-specialised units.

6.3. Methodology

The use and acceptability of the tool was a key part of the feasibility study alongside estimation of participant numbers and identifying time points for decision-making about oral intake. A feasibility study allows information to be collated on clinician and participant recruitment, eligibility, response rates, timings and protocol issues (Leder et al., 2012). Importantly they do not measure patient outcomes, as this is considered an aspect of a pilot study set-up (O'Cathain et al., 2015, Arain et al., 2010).

In order to establish good practice in the design and reporting of pilot studies National institute for Health Research (2014) a recommended reporting framework was employed for feasibility studies:

1. Integrity of the study protocol, which includes inclusion and exclusion criteria, staff training, storage of materials and assessment of the intervention.
2. Testing of data collection forms, to include participant forms and questionnaires.
3. Randomisation procedures
4. Recruitment and retention
5. Feasibility/acceptability of the intervention
6. Selection of the primary outcome measure

The results of the feasibility study contribute to the decision of whether a larger trial can proceed in similar settings and staffing. Criteria for estimating feasibility for future success include continuing with or without modifications or concluding that a study is not feasible (Lancaster et al., 2004). Thabane et al. (2010) emphasise the difference between pilot and feasibility studies and their required outputs for reporting. Regardless of statistical results, they note the importance of publishing all findings to improve researchers' knowledge. The use of descriptive statistics is encouraged in addition to capturing qualitative data to further explore any difficulties encountered (Arain et al., 2010). The capture of this information helps to identify specific challenges that would need to be managed to ensure further translation of the study.

6.3.1 Pragmatic approach

A pragmatic approach is designed to capture changes in normal practice following an intervention, without implementing any controls. This increases the applicability of results to that context. This approach is characterised by wide participant selection and clinician derived decision-making with directly relevant outcome measures. Reporting recommendations by CONSORT (Bugge et al., 2013, O'Cathain et al., 2015) provide guidance to ensure that bias is reduced through standard reporting to enhance applicability of results. Critical care involves multiple personnel in a quick changing environment, making controlled trials a challenge (Zwarenstein et al., 2008) and reduces translation into practice (Arnold et al., 2009). A pragmatic approach in critical care does not restrict daily practices, this can improve the uptake and use of a new intervention and future generalisability.

One study argued that RCTs are seen as the gold standard method of evaluating the effectiveness of an intervention. These are usually carried out in large homogenous patient groups to satisfy statistical significance. However, this limits the involvement of smaller patient groups, such as CSCI and oropharyngeal dysphagia, leading to an absence of robust evidence-based guidance (Kahn, 2009). By employing a pragmatic approach in their study of post-operative nutritional support, Bell et al. (2014) could use broad inclusion criteria and flexible considerations for delivery of intervention, with patient

relevant outcomes. A pragmatic approach for CSCI patients would permit greater patient participation and generate outcomes that are relevant to current care delivery.

6.3.2 Study aims

In the first phase, this study aimed to identify the usual clinical decision-making processes relating to evaluating swallow saftey in CSCI patients within a non-specialised acute unit. In the second phase, the use of a swallow screening tool for CSCI patient was evaluate in terms of acceptability by staff. The study did not aim to change practice, but to capture existing processes and procedures. This would help to inform a future multi-site study.
The following research questions were posed:

1. When are decisions made about commencement of oral intake for CSCI patients?
2. What methods are used to screen for swallowing problems in CSCI patients?
3. Who routinely decides on swallow safety and commencement of oral intake?
4. Can a spinal-specific swallow screening tool improve the timing and clinical decision-making process in non-specialised units?

6.4. Methods

6.4.1 Ethics

National Health Research Authority approvals were obtained (Project ID 129588) with site-specific agreements for consent for staff involvement to identify their profession only (Appendix 3). No patient consent was required as patient identifiable data was not collected.

6.4.2 Screening tool development

The DAISY swallow screening tool was developed from topic areas that gained consensus in the Delphi process (chapter 5). The term DAISY is an acronym for ‘dysphagia following acute cervical spinal cord injury’. Twelve components were derived from the agreed statements on co-morbid factors, screening and identification. The steering group of clinical professionals, previously involved in

the Delphi study, reviewed each component and decided whether it was easily identifiable in clinical practice for screening purposes. The items were grouped into three areas of risk for the purposes of the tool (Table 6.1). Firstly, injury risk factors which included co-morbid factors: level and severity of injury, brain injury and cervical spine surgery; secondly, clinical risk factors included need for intubation, ventilation, tracheostomy, and nutritional support; thirdly, urgency factors reflected clinical symptoms of aspiration, specifically increased need for suction and oral hygiene, spiking pyrexia and chest infection. The steering group agreed that the presence of any one factor within injury risk or clinical risk would require a referral to SLT for swallowing assessment. If signs of urgency were evident, a change to clinical management would be required.

To avoid a hierarchical or prioritisation structure, the tool was organised into a circular arrangement for the purposes of the feasibility study (Appendix 26). This made the tool easily identifiable and kept the theme of the 'DAISY' structure.

Table 6.1 DAISY swallow screening tool components

INJURY RISK FACTORS	
Co-morbid factors	Brain injury/cognitive deficit
Level of Injury	Cervical SCI C1-C7
Severity	Complete or incomplete injury
Cervical spine surgery	Anterior or posterior cervical spine surgery
CLINICAL RISK FACTORS	
Intubation	Over 48 hours
Tracheostomy	Cuffed or uncuffed tube
Ventilation	Requiring up to 24 hours ventilation
Nutrition	Reduced nutritional intake
URGENCY	
Chest infection	Recent chest infection
Pyrexia	Spiking pyrexia
Oral hygiene	Increased need for oral care
Suction	Increased need for suction

6.4.3 Development and use of decision forms

Each phase of the study required a decision form to be completed every time the DAISY tool was used (Appendices 27 and 28). This collected data on the date of use and profession using it, as well as brief details about the CSCI

patients, namely diagnosis, date of injury, baseline feeding status and post-screen feeding status. The forms used tick boxes for quick and easy use and free-text comment boxes to include details. These were reviewed by the steering group and principal investigators at each site. Key comments were for fewer free text boxes, so options for professional role and feeding status were listed so that these only needed to be ticked or circled. Once incorporated, a revised form was sent out and approved by same group.

6.4.4 Site recruitment and infrastructure

Two sites were selected for the feasibility study. These were both major trauma centres with an intensive care unit that took primary admissions for acute CSCI patients (Table 6.2). Site one was a neurological ICU with 14 beds and site two was a 44-bedded mixed acute critical care unit. Both sites were linked referral sites to a spinal injury unit, with an established outreach team. These were considered to be representative of other major trauma centres who admit SCI patients. Both sites reported having routine access to SLT for tracheostomy patients for both communication and oropharyngeal dysphagia assessments (Table 6.2). Each site routinely placed NG tubes to manage gastric aspirates following paralytic ileus and also commenced early enteral feeding. Trials for oral intake were only considered when a patient had the tracheostomy cuff deflated or after tracheostomy tube removal. Multi-disciplinary decisions took pace at weekly ward round meetings at both sites, where all patients would be discussed. Data regarding referral rates were obtained from the Spinal Outreach Service at the linked SIU.

Principal investigators (PI) were recruited for each site whose role it was to oversee the completion and collection of the decision forms and support staff training for the new tool. At both sites the role of PI was taken up by research nurses attached to the critical care unit, as they had time allocated for carrying out studies. Several set-up meetings took place with the AHP staff and PIs on each site to identify existing pathways for CSCI patients relating to the commencement of oral feeding, estimated SCI patient admission numbers, timing of decisions and personnel to be involved. Timings for local agreements and logistics of study set up resulted in varied start dates for the two sites. Site one commenced phase one in early October 2016 and phase two in late

November 2016, with completion at the end of February 2017. Site two commenced phase one in early November 2016, phase two in mid-December 2016 and completed in mid-February 2017.

Table 6.2 Comparative features of each unit participating in the feasibility study

Site features	Site 1 (NICU only)	Site 2
Level 3 beds	14	44
HEMS admission	yes	yes
No. of ICU staff	78	240
Staff training:	Face-to-face: 37 nurses, 1 registrar Video link sent to all	Video link sent to all
SLT referral access	Routine SLT referrals for all tracheostomy patients	Routine SLT referrals for all tracheostomy patients
Spinal pathway	Early NG feeding Cuff down for oral intake	Early NG feeding Cuff down for oral intake Wean and transfer off ICU
Use of nurse swallow screen	No	No
MDT decisions	Weekly ward round	Weekly ward round
Link to spinal outreach team	Yes	Yes
Average monthly SCI referrals (range)	7.6 (1-13)	4.7 (1-8)
Average monthly cervical and thoracic SCI referrals	5.6 (1-11)	3.8 (1-8)

NICU=neurological intensive care unit

6.4.5 Participant recruitment

In view of the small numbers of CSCI admissions, no participant recruitment size was set, instead each site was asked to complete ten forms for each phase of the study. A decision form was completed each time a decision was made about oral intake. This may be more than once per patient during the study phase. Once completed by the clinician, the forms were placed in a sealed box on the ward. This limited the risk of forms being lost or altered. The box with forms were collected by the lead researcher at the end of each phase for data analysis. The criteria for participant inclusion were any newly diagnosed SCI patient over 18 years admitted to the ICU with an injury to the thoracic or cervical level with any ASIA score or co-morbidities.

6.4.6 Study protocol

6.4.6.1. Design

A pragmatic prospective observational feasibility study was carried out at two major trauma centres in London who were primary admission sites for SCI patients. As admissions for SCI were unplanned, a pragmatic approach was employed to allow for variations occurring in usual clinical practices for

participant recruitment and timings of screening. The study was divided into two phases: In phase two, the screening tool was used for decision-making alongside usual care (Figure 6.1). No controls were set and the screening tool would be used within normal practice to ensure greater relevance and generalisability to practice.

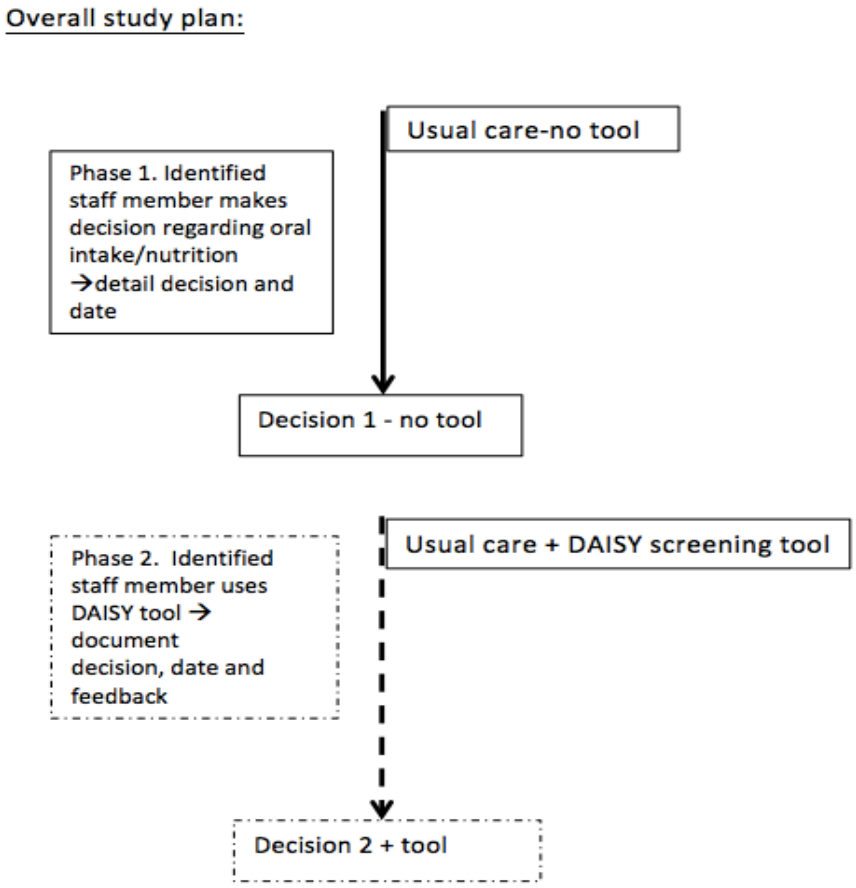

Figure 6.1 Two phase pragmatic observational feasibility study

i. Phase one

In phase one, staff were required to document their clinical decisions regarding the commencement of oral intake for every cervical and thoracic SCI patient. This was documented on the decision form either by the PI or team member. The patient's level of injury and date of injury were recorded in order to verify appropriate use of inclusion criteria and timing of decisions. Staff had to document the profession making the decision and date of decision to help

identify any patterns in clinical practice. Phase one was estimated to last six weeks or until ten decision forms had been completed. At the end of this phase, the forms were collected and each site prepared to receive training on the DAISY screening tool.

ii. Screening tool training

In preparation for the second phase, staff were required to be trained on the components of the screening tool, how to identify these features and complete the form. The site PIs selected the staff that required training, which took place either face-to-face or through an online training video lasting less than three minutes. This was created specifically to address the issue of training large numbers of nursing, medical and AHP staff working on the units. The video provided standardised instructions (Appendix 29) on using the DAISY swallow screening tool and was distributed electronically to staff or used in teaching sessions led by the site PI.

iii. Phase two

Once staff were trained, new decision forms were provided with the inclusion of the tool to prepare for the second phase. Feedback was also sought on ease of use of the tool. Four questions asked if the tool was easy to understand, easy to use, whether it was suitable for use by any member of the team and beneficial for use with SCI patients. Staff were required to tick one of five boxes on a Likert scale ranging from disagree strongly to agree strongly, with an additional comments box.

6.4.7 Data analysis

Data collected on the decision forms included the number of days post-injury that the screen was done, the professional carrying it out and the patient's level of injury. A form was used for each time a decision was made about commencing oral intake, so these were grouped by diagnosis and level of injury in order to identify the number of decisions made per patient. The data was inputted into an excel spreadsheet at the end of each phase of the study for analysis and feedback to each site. Feedback sores were collated and averaged per question for each site. Comments from post study meetings and

informal interviews with the PI and key staff were collated as qualitative data although no analysis took place as this was very limited.

6.5. Results

The results will be reported in line with the previously mentioned framework for feasibility studies (Bell et al., 2014) to review protocol integrity, data collection forms, recruitment and acceptability of the tool with additional qualitative staff feedback (Lancaster et al., 2004).

6.5.1 Protocol integrity

Using a pragmatic approach, inclusion criteria was broad and decision forms indicate that a range of cervical and thoracic level SCI patients were included for screening, with each site identifying similar numbers of CSCI patients (Table 6.3). The nature of injury was not recorded but it was evident that some were traumatic and some non-traumatic, with variability of surgical involvement. Site one made 21 decisions for six patients in phase one and 12 decisions for 3 patients in phase two, using the tool. Site two made five decisions for four patients in phase one and seven decisions for four patients in phase two. At both sites the PI often completed the forms rather than the staff member making the decision, with information obtained from the medical notes or following discussion with the team.

Before commencing phase two, attendance at staff training in the use of the DAISY screening tool was recorded at each site. Both sites distributed the video link to all staff, however there was no verification on who had watched it. Site one carried out face to face training with 37 nursing staff and one doctor as part of their regular ward training sessions. Site 2 did not carry out any classroom training and only used the video for training.

6.5.2 Data collection forms

The forms for phase one and two were paper based, although both sites used electronic patient records. The PI's were responsible for identifying suitable patients for screening and had to provide the paper forms and screening tool for completion. The tick boxes were completed more frequently than the free-text

comments sections. This limited the data collected on the reason a clinical decision was made in both phases one and two.

Table 6.3 Participant recruitment and decisions per site and per phase

	SITE 1		**SITE 2**	
Cervical level injury	7		6	
Thoracic level injury	2		2	
PHASE ONE	21 decisions for 6 patients		5 decisions for 4 patients	
	Nurse	4		1
	Doctor	7		2
	SLT	4		2
	Dietitian	6		0
PHASE TWO	12 decisions for 3 patients		7 decisions for 4 patients	
	Nurse	5		3*
	Doctor	5		3*
	SLT	2*		0
	Dietitian	2*		0
	Team	0		2

*more than one professional involved

6.5.3 Staff characteristics

Site one showed a diverse range of staff making decisions about commencing oral intake, but few decisions reported as a team (Table 6.3). All sites reported more frequent decisions about oral intake made by doctors, on occasions this was jointly with nurses (Site 2, phase 2). There was no dietetic involvement during either phase at Site two, and greater involvement at site one in phase one than phase two. The SLT was involved more in clinical decisions at site one than site two.

6.5.4 Recruitment

Patient selection in both phases demonstrated that both high and low level CSCI patients and thoracic level patients were selected appropriately and required decisions to be made about oral intake. For this study, data was collected on the number of days from injury to assessment and the number of decisions per patient in each phase (Table 6.4). The number of decisions varied

per site but not across the phases, which may be due to the influence of the existing site protocols.

The average time to decision reduced for both sites in phase two. At site one it reduced from 5 days to 2.2 days, a 56% change. On site two this was a 21% change from 6.4 to five days. The average number of decisions made per patient showed a slight increase from 3.5 to 4 (14%) for site one and 1.25 to 1.75. (40%) for site two.

Table 6.4 Average days to decision and decisions per patient by site and phase

Average number of days from injury to decision (range)	**SITE 1**	**SITE 2**
Phase one	5 (0-20)	6.4 (0-18)
Phase two	2.2 (0-5)	5 (0-20)
Average number of decisions per patient (range)		
Phase one	3.5 (2-8)	1.25 (1-2)
Phase two	4 (1-7)	1.75 (1-3)

6.5.5 Acceptability of the tool

This was evaluated through the feedback forms and post-study meetings. Site one submitted four feedback forms, and site two had completed six forms (Table 6.5). Using the mean scores for each question, site one averaged a high level of support for the tool (98.75%), whereas site two did not agree with the statements about usability, benefits and ease of understanding, scoring only 44% of the maximum score.

Table 6.5 Feedback scores at end of phase two for site one and site two

Tool feedback survey*	Site 1 Mean score (n=4)	Site 2 Mean score (n=6)
Tool was easy to understand	4.75	2.17
Tool was easy to use	5	2.17
Tool can be used by any member of the team	5	2.17
The tool would be beneficial for use with SCI patients	5	2.33
TOTAL out of 20 (%)	19.75 (98.75)	8.83 (44.17%)

*Likert scale 1= disagree strongly, 2=disagree, 3=neutral, 4=agree, 5=agree strongly

6.5.6 Staff Feedback

Feedback from each site was gained at the end of each phase, mostly through conversation with the PI and key involved staff, such as PT or SLT. Site 1 reported that nurses were unsure about their decision-making in phase one as they had no standard clinical guidance, so relied on routine practices. In phase two, site 1 nurses reported that using the DAISY tool helped to direct nurses decisions, by raising awareness of specific risk factors. They gave an example of identifying a patient with an NG who was coughing when drinking and had had no swallow assessment, so he was picked up as a risk and referred to SLT. Another nurse reported that they usually leave the swallowing decisions to the PTs but felt empowered to make a decision themselves by using the items within the DAISY screening tool.

A total of three free-text comments were submitted in the feedback forms:
Site one commented:

> *"tool is very useful and will help prevent aspirations/deteriorations"*

Two comments from site two reflected on the tool in the context of their existing structured protocol:

> *"[Query the] use of tool, as protocol in place ensuring NG fed + SALT. Reviewed every 7 days in [ward round]"*

> *"Decision not related to tool, tool not relevant here"*

6.6. Discussion

The value of screening for oropharyngeal dysphagia has been supported in studies across a number of patient populations (O'Horo et al., 2015, Speyer, 2013). However, these have excluded patients requiring tracheostomy, ventilation or at high risk of silent aspiration, such as the CSCI patient group (Shin et al., 2011). Despite consistent recommendations for early swallow screening for CSCI patients (Shin et al., 2011, Chaw et al., 2012, Kirshblum et al., 1999) to date no screening tools have been proposed. This is of particular importance to guide staff managing CSCI patients in non-specialised settings and making early decisions on care. Existing studies on oropharyngeal

dysphagia assessment with CSCI patients have been sited only in specialised units, where staff have specialist skills and expertise with this population. This limits the generalisation of their findings. Undertaking the current study in the primary admission site for SCI patients, namely MTCs, permits a better understanding of the challenges for staff in these settings and the process of decision-making. The following discussion will consider the results of the feasibility study in relation to the research questions posed in section 6.4.2.

6.6.1 Current clinical practices

In the absence of national protocols, local standards for practice determine timing, frequency and method of identification of swallowing problems. The study revealed differing practices at each major trauma site in the study, despite using established clinical pathways. Multiple decisions were made about oral intake for SCI patients at varying time points. This involved a number of different professionals, which highlights the complexity of SCI and need to consider different clinical issues, such as respiratory function and nutritional demands, before commencing oral intake.

There is a paucity of studies reporting on the timing of the decision-making process for oral intake. A recent study revealed pathway variations for different tracheostomy patient groups based in the same unit (Pryor et al., 2016a). Most of the heterogeneous caseload were permitted oral intake once cuff deflation was established and secretion management was intact, however SCI was the only patient group where oral intake commenced with tracheostomy cuff inflated with additional enteral nutritional support. This contrasts with the care pathway identified at the two sites in the feasibility study, which required cuff deflation before considering commencement of oral intake. This appears to link the decision about swallowing with respiratory function and ventilator needs, which have been identified as contributing factors to oropharyngeal dysphagia in CSCI (Shem et al., 2012a).

Both sites had reported having weekly MDT meeting for clinical discussions where decisions about oral intake would take place. The study data demonstrated that in fact decisions about commencing oral intake happened on a more frequent basis, sometimes daily. Even those who were on NG feeding

were reviewed to see if they could recommence oral intake, as that appeared to be the goal. For those requiring enteral tube feeding, current national guidance for the nutritional management of acute patients with dysphagia does not specify the frequency of review required (National Collaborating Centre for Acute Care, 2006). The key recommendation for those with dysphagia is a 2-4 week trial of enteral feeding with an assessment of future needs if problems persist. CSCI patients admitted to MTCs are expected to have short lengths of stay in line with national recommendations for prompt transfer to specialist units (National Institute for Health and Care Excellence, 2016). With limited bed capacity for ventilated patients, transfers to SIU are delayed (Spinal Injuries Association, 2015). This leaves non-specialised units with the responsibility for making decisions about long-term feeding, such as PEG. It was not possible to capture whether these decisions took place in the study sites due to the short duration of each phase and small admission numbers. Findings from a study on malnutrition rates in SCI patients admitted to SIUs suggests that these decisions are often deferred (Wong et al., 2012a). With small samples at both sites and existing protocols, it was difficult to evaluate whether using the swallow risk screening tool prompted earlier monitoring of oropharyngeal dysphagia risks. The results did identify that daily screening took place for some patients, rather than weekly decision making that had been reported prior to the feasibility study.

Both the sites selected for the study had established clinical pathways for acute spinal care. However, this is not representative of all MTCs or non-specialised units, as reported in the survey study (chapter 3). The pathway included routine placement of NGTs in tracheostomy patients followed by referral to SLT for swallowing assessment, in line with national recommendations by NCEPOD (2014). No routine swallow screen was previously used and decisions about oropharyngeal dysphagia risk were made based on signs and symptoms, such as presence of cough or respiratory issues. In the absence of guidance that specifies optimal time for swallowing screening (National Institute for Health and Clinical Excellence, 2009) this study identified that for both sites swallow evaluation usually took place within the first five to six days post-injury. Additionally, between three to eight decisions were being made per patient during the period of the study. It is unclear whether this was due to changing

medical status or development of clinical signs of oropharyngeal dysphagia, but this provides valuable data on the decision-making process. Cross-site comparisons of clinical activity was limited by the lack of comprehensive patient data collected. A future study would benefit from collecting patient data and outcomes to allow case comparisons and generalisability of results.

6.6.2 Multi-disciplinary involvement

The results reflected the involvement of multiple professionals in making decisions about oral intake however decisions made by a team were rarely documented. This may have been influenced by the availability of staff as well as their own routine practice. Doctors and nurses tended to lead the decisions with marked variability of dietetic and SLT involvement between the two sites. This may impact on decisions for long-term feeding (Rozeboom et al., 2012, Cameron et al., 2009). Although there is little documentation to support MDT input for oropharyngeal dysphagia management (Batty, 2009) national guidance recommends collaborative team working as good practice (Intensive Care Society, 2015). Studies on team interventions have demonstrated Improvements to the outcomes of ventilated patients, (Salipante, 2002), tracheostomy care (Cetto et al., 2011, Mitchell et al., 2013, Speed and Harding, 2013) and SCI rehabilitation (Rozeboom et al., 2012, Cameron et al., 2009).

Both sites had reported having an established protocol for SCI patients that routinely initiated early NG feeding and SLT involvement for those with tracheostomy, in line with national guidance (National Confidential Enquiry into Patient Outcomes and Death, 2014). Staff at both sites reported that NG feeding continued when patients transferred onto other wards or hospitals, postponing decisions made for oral intake. Despite this, both sites showed an increase in the number of decisions made and a decrease in the number of days to start decisions, so they were evaluating patients for commencing oral intake sooner and more frequently when using the tool. In terms of feedback, staff from site one found the tool gave them clear direction and increased awareness, whereas staff at site two felt that it did not provide any additional value due to their existing protocol, despite the changes in practice when using the tool.

6.6.3 Limitations

There were a number of limitations in this study; firstly, estimating sample sizes was not a requirement for a feasibility study. Only ten forms per phase were requested based on previous referral numbers, with an expectation that one to two decisions would be made per patient. During the study period, the number of SCI admissions to each site reduced, resulting in fewer patient numbers. Despite this, site one generated more than two decisions for some patients, submitting over 20 forms in phase one. Estimating sample sizes for a future study needs careful consideration, as admissions numbers are erratic. Ideally a multi-site study would employ a pragmatic approach to inclusion criteria to ensure wide patient selection.

As both sites were MTCs, they had protocols in pace for the acute management of CSCI patients and this is likely to have reduced the utility of the DAISY screening tool. A future study would benefit from trials in multiple units, to include DGH and other hospital settings that admit SCI patients for prolonged periods but do not have any existing protocols in place. This would also permit set-up of a control group to evaluate value of the tool rather than a progressive change in clinical decision-making.

Reduced sample sizes may also have contributed to poor staff engagement, especially at site two which was a much larger ICU with over 200 staff. Although the PIs at each site were responsible for engaging with nursing, AHP and medical staff, limited time and wider commitments made it difficult to involve and train everyone. The training video developed for the screening tool was designed to reduce the time commitment for face-to-face training, however monitoring completion of forms became the main remit for the PIs. As a result, the PIs were frequently the ones to complete the decision forms, based on staff discussion and documentation in the medical notes. This may have biased the feedback responses in phase two, although this would not have had an effect on clinical decisions made by the team.

Finally, the recording of data on the paper forms varied at each site with missing information in phase two from both sites, despite the same form being used with minor adjustments. Staff were asked to use the DAISY screening tool to circle the factors involved or write them on the form. This would have been used to

identify differences in the factors used to make decisions. However, this was not routinely done, limiting any comparisons pre and post tool. Using paper forms was also a physical challenge as there was no dedicated area in each bed space for paper documentation, with established electronic systems. This took up PI time to extract data from the electronic notes onto the forms.

6.6.4 Future directions

To further develop the tool, validation of its sensitivity and specificity is required. In the absence of a gold standard screening tool this would require comparison with a gold standard assessment such as FEES or VFS. For CSCI patients who are unlikely to be able to transfer to radiology easily, bedside FEES is the preferred option. To ensure an adequate sample size, multiple sites are needed, each of which will require an established FEES service. Currently, not all SLT departments have the equipment or training to use FEES, so this would be a large body of work to establish prior to a validation study.

To address issues of staff recording decision data, a simple scoring system could be implemented similar to other existing ICU screening tools with scores of 0 or 1 used to indicate absence of presence of a feature, with total score reflecting severity. Weighting each factor would help to define the intervention required, however currently there is insufficient data from existing studies to calculate this. To ensure regular access and utility, it may be beneficial to develop an electronic version of the tool that can be embedded into existing electronic patient records. This could generate prompts to complete mandatory sections to assess oropharyngeal dysphagia risk as part of an early care pathway.

6.7. Conclusion

This feasibility study has demonstrated the challenges of undertaking a clinical trial within different critical care units with a variety of standard practices that cannot easily be controlled, hence benefitting from a pragmatic trial approach. With limited resources in critical care, a tool that focuses on risk factors for oropharyngeal dysphagia in CSCI could improve the process of clinical decision-making through earlier review. The DAISY tool focuses on the

presence of specific impairments rather than observed behaviours, which may be absent in the CSCI population.

Although the feasibility study could not demonstrate a positive change in clinical decision-making, this may have been superseded by existing care protocols. Further evaluation across multiple sites for extended time periods would generate greater data on utility and any impact on clinical outcomes for CSCI patients, which is currently lacking. Integrating the tool with best practice recommendations generated from the Delphi study (chapter 5), would overcome the inconsistencies of care for CSCI patients with oropharyngeal dysphagia, reported in the survey of clinical practice (chapter 3) and by participants and their families in the interview study (chapter 4).

7. Final discussion and future directions

This final chapter provides an overview of the four studies reported in chapters three to six. Implications for clinical practice will be discussed in addition to the limitations of the studies. Recommendations are made for future research based on the findings of these studies.

This study was originally conceived and developed from the perspective of a clinician working in a specialised spinal unit with a background awareness of mixed practices for oropharyngeal dysphagia across referring units. Delayed admissions for those requiring specialist SCI interventions have increased over time in UK due to growing demand and limited bed capacity (Spinal Injuries Association, 2015). Those with oropharyngeal dysphagia often have correspondingly complex respiratory impairments, requiring admission to one of only 28 national respiratory SCI beds. Few studies have investigated the care of SCI patients in non-specialised units as the numbers are small and located across multiple sites (Donovan et al., 1984). For studies that have compared outcomes in specialised and non-specialised units, oropharyngeal dysphagia has not been a specific consideration, although it would have contributed to complications, which are often reported (Smith, 2002, New et al., 2011a).

Chapter 2 provides a review of the literature on the multi-factorial etiology and incidence of oropharyngeal dysphagia in CSCI. These studies are predominantly retrospective studies and based in specialised units, providing limited generalisability to oropharyngeal dysphagia management in non-specialised units. The primary aim of the research was to understand variations in clinical management of oropharyngeal dysphagia for CSCI patients across specialised and non-specialised units. This was explored through an online survey of multi-disciplinary staff working in both specialised and non-specialised units reported in chapter 3. The following study, chapter 4, recorded the lived experiences of people with CSCI and oropharyngeal dysphagia during their hospital admission. The data from these two studies would identify whether differences were due to variations in unit practices or professional roles which would help to guide future recommendations.

The second aim of this research was to develop a tool to support consistent oropharyngeal dysphagia identification and care for CSCI patients. Chapter 5 describes the recruitment to the expert panel and process to generate expert consensus on the risk factors for oropharyngeal dysphagia in CSCI patients and methods of identification and management. The results from two rounds of the Delphi consensus provided the basis for a swallow risk screening tool and best practice recommendations. Chapter 6 reports a feasibility study evaluating the utility of the screening tool in two non-specialised units and describes the challenges to patient recruitment and staff engagement, that reflect the difficulties of undertaking studies in this small specialist clinical area.

7.1. Summary and implications of the research

The findings of the first study provided details on the wide variety of service provision to acute SCI patients, which has not been acknowledged in previous reports on current service delivery (CRG for Spinal Cord Injury, 2016). Primary admission following SCI is assumed to be to a MTC with a recommendation for contact with specialised SIUs within 4 hours to agree treatment plans and facilitate transfer (CRG for Spinal Cord Injury, 2016) (Figure 7.1). With a total of 22 MTCs and eight SIUs in England, the survey expected responses from 30 units, however staff from 64 units reported admissions to SCI patients. This provides evidence that SCI admissions do not in reality, follow a clear pathway and involve many more units. Subsequent analysis compared decisions made by staff in specialised and non-specialised units. Links to a SIU were reported by less than a third of staff in non-specialised units suggesting a gap in access to specialised support. This is of concern, especially with prolonged admissions in these units and the limited capacity for outreach staff to minimise complications whilst awaiting transfer.

With regards to knowledge and skills, there were areas of similar practice, such as tracheostomy management and nutritional decisions, however oropharyngeal dysphagia skills were generalised from other population groups and did not reflect the adjustments needed for CSCI patients with an inability to cough. A key variation in practice was the use of vital capacity measures to

monitor respiratory function reported to be used by less than half of staff in non-specialised units compared to over three-quarters of staff in specialised unit. This is likely to have significant impact on weaning processes, as identified in studies of failed weaning in SCI (Atito-Narh et al., 2008) despite guidance established by RISCI and supported by the Intensive Care Society (2012).

In the absence of clear guidance on swallowing safety for those with tracheostomy, clinical decisions varied for screening, assessment and management across unit types and professionals. The use of blue dye and thickened fluids for oropharyngeal dysphagia by non-SLTs in non-specialised units demonstrated poor awareness of the specific impairments in CSCI and could put patients at greater risk of developing complications. There is currently no agreement on the safety of swallowing with cuff up or down and this was reflected in the range of mixed responses. Although specialised units did not routinely feed with cuff up, all units reported using this technique sometimes. Better clinical evaluation is required through the use of FEES, which was employed more in specialised units.

Algorithm Two: Adult Patient with SCI taken to taken to Major Trauma Centre

Pro-forma Algorithm for Joint Major Trauma Network and SCI Centre Protocols
Algorithm Two: Adult Patient with SCI taken to taken to Major Trauma Centre
Name of Trauma Network…… Name of Spinal Cord Injury Centre……
Date agreed…… Review Date……..

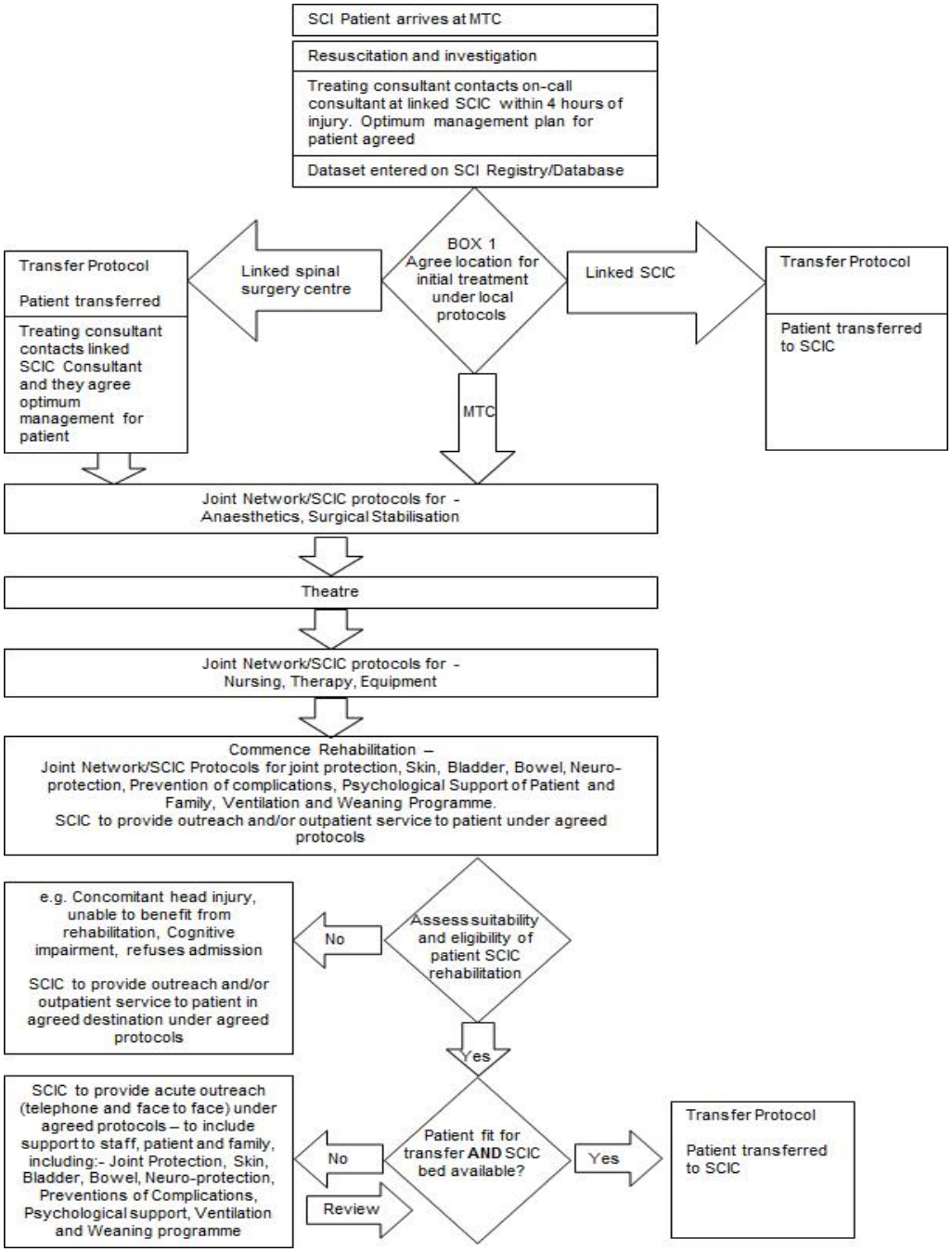

Figure 7.1 Decision algorithm for acute SCI admission to MTC
(Respiratory Information for Spinal Cord Injury, 2012)

The interview study (chapter 4) provided an opportunity to uniquely capture the experiences of CSCI patients with oropharyngeal dysphagia during their hospital admission. Although previously reported studies have detailed the psychological adjustment to SCI (Sand et al., 2006), there have been no reported findings of those with additional impairments to swallowing or communication, especially during acute care. These interviews explored experiences in both non-specialised and specialised units and highlighted the complexity of the participants' condition. The interviews engaged eight people with CSCI and their carers who shared the range of psychological and emotional challenges following a devastating injury.

Transfer to specialised unit was expected to occur soon after diagnosis and gave hope for recovery. In reality, all participants waited over two months and half of them over six months, with interim transfers to other non-specialised units with little information provided by staff. Sumida et al. (2001) considers six months post injury as being the chronic phase after which little motor recovery can happen. Others have suggested that timing of admission to a specialised unit is a prognostic indicator for functional recovery, with evidence of improvement for those admitted within 30 days (Scivoletto et al., 2005). In the current study, participants who were transferred to a specialised unit had high expectations for recovery, that were not always realised, giving a sense of lost opportunity. Despite the small sample size, it is evident that the potential for recovery is reduced by delayed admissions especially in the south of England. This highlights the inequity in accessing specialised care for CSCI patients who require additional respiratory support (Spinal Injuries Association, 2015)

Participants reported that care in non-specialised units was usually provided by teams who often admitted lacking specialist skills for SCI. All participants experienced being made NBM following a variety of procedures to diagnose oropharyngeal dysphagia. There were little or no specific interventions to enable a return to oral intake. The lack of ability to communicate basic needs due to ventilation via a tracheostomy, increased the sense of isolation and frustration. Although this supports the findings in the wider literature on the experiences of short-term ventilated patients (Carroll, 2007, Karlsson et al., 2012a), people with CSCI are unable to access other communication methods

and may remain permanently ventilated. These results identify a need for SCI-specific education and guidance for staff across non-specialised units in order to ensure the provision of psychological support and early interventions, especially for those with oropharyngeal dysphagia and communication impairments. This would reduce the loss of potential recovery due to delayed SIU admissions.

To address the need for guidance in the absence of empirical evidence, the third study (chapter 5) used a Delphi process to generate expert consensus on the risk factors to identify oropharyngeal dysphagia and the interventions required to maximise recovery. Twenty-seven international multi-disciplinary clinicians participated in the Delphi. Relevant topic areas that required consensus were developed through a review of the literature, cited in chapter 2. The survey results (chapter 3) were used to check for relevance in current practice. After two rounds, 73% of the 85 statements achieved consensus. High levels of agreement were generated for areas of clinical management and therapeutic interventions. There was unanimous consensus that NG feeding should be started if oropharyngeal dysphagia is evident and that oropharyngeal dysphagia was not a permanent state and should improve. These statements alone provide non-specialist clinicians with clear directions for management. Although risk factors were agreed, there was less consensus on how to identify oropharyngeal dysphagia.

The experts agreed that neither blue dye tests or bedside swallow evaluations (BSE) were reliable to screen for oropharyngeal dysphagia in CSCI. This challenges the clinical practice reported by staff in the survey (chapter 3) who routinely used both. It also contradicts the findings of a study reporting high sensitivity and specificity of BSE to diagnose oropharyngeal dysphagia in CSCI when compared with VFS (Wolf and Meiners, 2003, Shem et al., 2012b), especially as this was carried out by an expert SLT in a specialist unit, limiting applicability to staff in non-specialised unit. The routine use of VFS as an assessment did not gain consensus, with experts commenting on patient access issues. The use of FEES only gained majority agreement, which may reflect mixed practices between professions on the panel and their geography. In the UK, SLTs undergo rigorous competency-based training to carry out

flexible nasendoscopy (RCSLT, 2015) whereas, this is not a routine procedure carried out by SLT services in all countries.

The range of potential SLT interventions with SCI patients have previously been categorised (Gordan et al., 2012) however, SLT provision is not routine and relies on referral by another health professional. The interview participants in chapter 4, expressed their wish to return to normal swallowing and speaking as a goal in their recovery. The expert panel in the Delphi study supported daily SLT intervention to achieve these goals for all patients. With regards to specific interventions, it was agreed that patients should be eating with cuff deflated and that this was acceptable in a semi-recumbent position. The use of thickened fluids with CSCI patients was not supported, which contradicts the clinical practices reported by staff in study 1 (chapter 3). This provides clear directions for staff in the clinical management of oropharyngeal dysphagia.

Based on the results of the Delphi, oropharyngeal dysphagia risk factors that achieved consensus were collated to develop a CSCI-specific swallow screening tool, entitled DAISY, an acronym for oropharyngeal dysphagia following acute cervical spinal cord injury. The last study, a pragmatic observational feasibility study, is reported in chapter 6. This evaluated the usability of the DAISY tool over two phases with staff in two non-specialised units who admit CSCI patients. During the first phase, staff recorded their current practice when making clinical decisions about oral intake for acute CSCI admissions. Prior to phase two, staff were given training on using the DAISY tool, following this they recorded their decisions using the tool as part of clinical practice. Interestingly, both sites reported having a pathway that required MDT clinical decisions, however phase one results demonstrated infrequent decisions made by differing staff at different time periods. The methods used to reach decisions about oral intake were often unclear and although the use of the tool was found to be beneficial at one site, it was not valued at the second site. As a feasibility study this provided insight into the challenges of setting up a multi-site study in critical care units and the need to engage with staff widely in advance.

The studies within this thesis have contributed knowledge and information about the care delivered to patients with CSCI from the perspectives of staff, patients and carers. The first two studies identified variations in practice that have significant emotional and physical consequences for CSCI patients who have to experience prolonged admissions in non-specialised units. The second two studies aimed to reduce the differences in practice by gaining expert agreement on risk factors for oropharyngeal dysphagia and best-practice recommendations, to support early identification of risk through use of a screening tool. It is hoped that this would enable involvement of relevant staff and prompt interventions to reduce complications and facilitate oral care and communication. The findings generated from the survey and interview studies, were rated by experts in the Delphi study to generate a range of best practice recommendations for the clinical management of five key clinical features, listed in table 7.1, namely oropharyngeal dysphagia, respiratory function, oral care, communication and nutrition.

Table 7.1 Study findings across five key areas summarising existing practice and changes to practice

Key areas	Existing clinical practice (as identified in study 1)	Changes to practice (following expert consensus in study 3)
Oropharyngeal dysphagia	• Use bedside screening evaluation (BSE) • Use of blue dye to assess aspiration • Use of thickened fluids to manage oropharyngeal dysphagia • Reliance of cough to indicate oropharyngeal dysphagia • Permit oral intake with cuff inflated • Upright position required • Delayed SLT involvement (after symptom development)	• BSE not reliable as oropharyngeal dysphagia screen as cranial nerve signs will be absent • Blue dye is an unreliable screen for oropharyngeal dysphagia • Thickened fluids should not routinely be used and may be detrimental due to pharyngeal stasis • Risk factors for oropharyngeal dysphagia should be ascertained if cough is absent • The need for ventilation should not restrict oral intake • Preference for oral intake with cuff down • Consider semi-recumbent position for oral intake • VFS not best assessment, FEES should be used in preference • Early involvement of SLT and dietetics to facilitate safe oral intake
Respiratory	• Local weaning protocols • Variation in capping and speaking valve use	• Use RISCI national weaning guidance • Encourage respiratory weaning, cuff deflation • Use vital capacity as a clinical measure • Aim for self-ventilation
Oral care	• Twice daily as minimum	• Regular oral hygiene • Oral moisturisation to manage dry mouth
Communication	• Mouthing and low technology aids	• Aim for verbal communication with cuff down and use of speaking valve
Nutrition	• NG feeding only when oral intake is inadequate or evidence of oropharyngeal dysphagia • PEG tube considered only after failed swallow assessment	• Routine early NG feeding • Transition to PEG if >6 weeks of NG feeding • Do not keep NBM

7.2. Strengths and limitations of the research

A key limitation to the studies requiring staff engagement, namely the survey study (chapter 3), Delphi study (chapter 5) and the feasibility study (chapter 6), was the need to involve multi-disciplinary staff. The survey required responses from multiple professions to provide representation of team decisions across units. Reflecting the size of the various professional groups, It captured more respondents from the larger professional groups such as nursing and physiotherapy and fewer respondents from the smaller groups such as SLT and dietetics. This may have influenced the results towards the actions of the larger groups, however this may still be considered representative of clinical practice. Ideally, it would have been valuable to target specific staff to participate in the survey, but it was not possible to identify specific staff working in these units, especially if they work across other services, as is often the case for SLT. This made relied on the sample being self-selective. To minimise bias, the survey was disseminated through a number of multi- and uni-professional networks. Staff who were less familiar with the clinical management of SCI patients may have excluded themselves, limiting the generalisability of results. Completion of the survey by 64% of respondents reflects a high level of cooperation and participation.

The methodology of the Delphi study had a number of limitations. It sought to recruit experts from five professional groups to achieve consensus relevant to day-to-day clinical practice. Despite having named nursing and dietetic staff that fulfilled the criteria for expert status, very few consented to participate in the Delphi, which may have reduced the possibility of consensus in certain areas such as nutrition or oral hygiene. One reported reason for reduced involvement was an inability to devote time over several months, which is a limitation of the Delphi process and a challenge for busy clinical staff. Attribution of expert status was a concern to invited nursing staff, who expressed a lack of confidence as an expert and were reluctant to express an individual opinion, despite quasi-anonymity. This reflects issues with the term ‘expert’ used in the Delphi and the expectation of having definitive knowledge in a specific area. The Delphi does

not claim to provide the correct answer to an area of uncertainty, but a consensus on agreed practice, against which further study can be investigated.

Setting up the feasibility study to evaluate usability of the DAISY screening tool, identified a number of limitations due to the complexity of the environments. A pragmatic approach was employed to accommodate variability in this clinical setting. Protocols were already in place in the two sites so motivation to participate in using a screening tool was a challenge. Delays to local ethics approvals shortened the length of time for each phase of the study and activity was dependent on CSCI patient admissions which were erratic. Selecting a principal investigator (PI) was problematic due to staff turnover and limited availability of time and resources. Over the short period of the study, one site found the tool of great benefit to inform nursing staff of risk factors and they subsequently requested to embed it into their existing pathway. The second site was a larger unit with high staff numbers, making it difficult to engage all the staff during each phase of the study. Consequently, staff reported that the tool provided little value to their existing protocol. Overall, this variation makes it difficult to demonstrate utility of the tool without further evaliuation at other sites without protocols.

Limitations to the interview study (chapter 4) included the recruitment of patient participants and the interview process. As CSCI patients remained in hospital or a care facility for extended periods, access was limited both for invitation to participate and the interview process. Staff at each site were asked to select suitable patients, however a number of invited participants did not make contact to participate and the reasons are unknown. Small participant numbers are common in qualitative studies with SCI patients. Often these have excluded those with tracheostomy and ventilation or limited communication ability. This study actively engaged with participants who had limitations to verbal communication to provide greater insight into the experiences of being non-vocal.

7.3. Recommendations and future research

Whilst exploring the current system of care for CSCI patients it was evident that delays to admission to specialised units were routine and often detrimental to patient care. The role of spinal outreach service is to facilitate the transfer to SIUs however, these services are often staffed by single professionals and do not routinely provide extensive education to staff and support to patients and families. Only one SIU has developed a multi-professional team approach in an attempt to mitigate the delays to admission. Although this does not overcome all clinical complications, it provides a valuable bridge with specialised spinal services and has demonstrated change to clinical practices in non-specialised units (personal communication, spinal outreach services, Stanmore on 1st March 2017).

SCI patients come into contact with multiple professionals in multiple specialities, which creates confusion for patients and can be ineffective for care. There was often evidence of team working between doctors and nurses however, there needs to be better understanding of the roles of the wider AHP staff and utilisation of the skills to maximise the impact of multi-professional care (Wheelan et al., 2003). This is particularly pertinent to oropharyngeal dysphagia management which relies on evaluation of respiratory function from the PTs, nutritional intake from dietitians, oral hygiene issues from nursing staff and general medical status from the doctors. Regular team discussions are required to ensure this information is up to date in order to make appropriate decisions and prognosis, which can then be shared with the patient and family.

The series of studies reported in this thesis highlighted the need for clinical guidance to direct decision-making in the management of oropharyngeal dysphagia in CSCI patients. The first step employs the DAISY screening tool as a checklist of risk factors (figure 7.2). In order to validate the tool, it requires a specificity ≥60% to correctly identify those without oropharyngeal dysphagia and a sensitivity ≥70% to correctly identify those with oropharyngeal dysphagia (Speyer, 2013). In the absence of validated screening tools for comparators, the gold standard assessment of FEES would be required for comparison of results. In line with previous validation studies, the DAISY swallow screening tool would

be first used with a CSCI patient and a decision made about oropharyngeal dysphagia risk and need for further assessment. Ideally all patients would then be followed up with a FEES examination to verify whether this risk is evident. A FEES assessment would provide an evaluation of pharyngeal and laryngeal function for swallowing effectiveness, airway protection, and sensory response to aspiration and penetration. This study would require multiple sites in order to generate an adequate sample size. A key challenge to a validation study is that currently FEES is not universally available or used as a routine assessment by SLTs in either specialised or non-specialised units (Hayton, 2016). To prepare the sites for participation, equipment and competency training would have to be established.

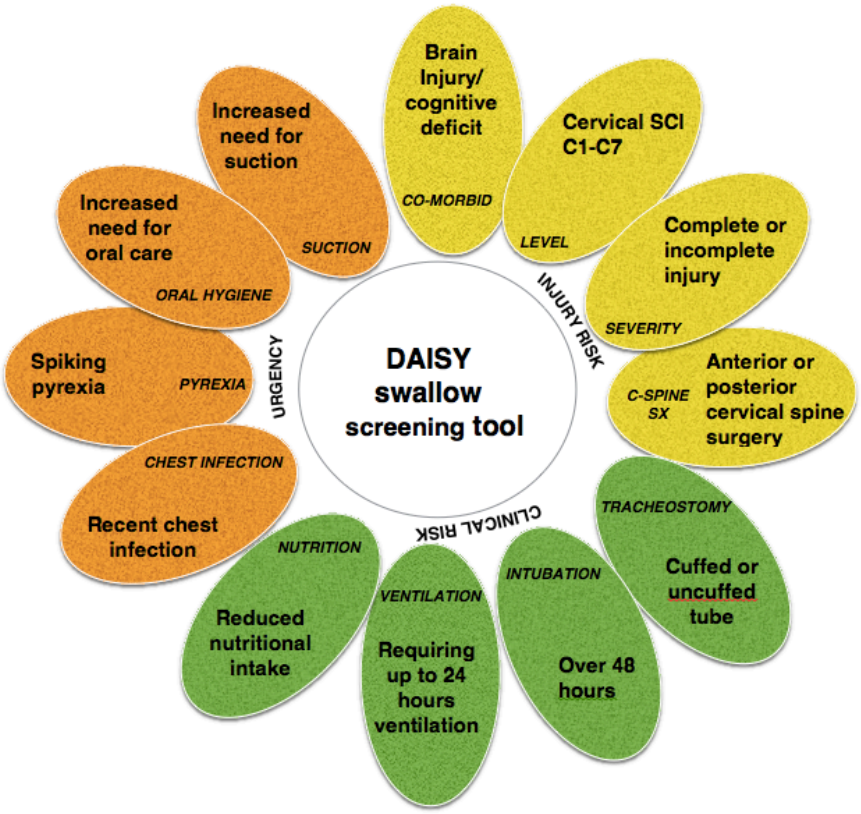

Figure 7.2 The DAISY swallow screening tool

Following on from a validation study, outcomes are required on both short term and long term impacts of early oropharyngeal dysphagia identification. This may include changes to lengths of stay, commencement of oral intake, respiratory complication rates and quality of life measures. Due to the prolonged admissions at non-specialised units, this will require engagement from multiple units and staff groups and supported by a programme of staff education. Once

screening and assessment become routine and reliable, studies can focus on effective interventions, currently poorly evidenced (Valenzano et al., 2016).

Lastly, further qualitative studies are required to explore the experiences of CSCI patients as they are often excluded from studies due to issues of recruitment or restricted communication ability. The additional involvement of family members in a longitudinal study would help to understand the course of adjustment to oropharyngeal dysphagia alongside physical impairments. This would contribute to wider staff awareness of the difficulties encountered and the long term impact that they could influence through their care.

7.4. Conclusions

This thesis contributes new and significant information to the knowledge of the identification and management of oropharyngeal dysphagia in CSCI. With the incidence of CSCI increasing alongside age and comorbidities this is likely to increase the prevalence of respiratory dysfunction and oropharyngeal dysphagia (Devivo, 2012). Evidence supports early interventions within specialised care but UK bed capacity is currently limited and cannot meet the demand for respiratory CSCI patients. Instead, it is preferable to train staff in non-specialised unit to screen for oropharyngeal dysphagia risks, in order to deliver early interventions and prevent the development of associated complications. Following further validation, the DAISY screening tool has the potential to deliver a solution that is accessible for staff and benefits patient care used with best practice recommendations. Prospective research in this clinical area is challenging, however further evidence is needed to support the provision of improved patient care.

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Appendices

1. Ethics approval for Study 1 (staff survey) and study 2 (participant interviews)
2. R&D approval for Study 3 (Delphi study)
3. HRA approval for Study 4 (Feasibility study)
4. Steering group survey comments
5. Final survey questions and response options
6. Heatmap of survey respondents across the United Kingdom
7. Survey participant information sheet
8. Survey responses across specialised and non-specialised hospitals
9. Survey responses across professional roles
10. Topic guide for semi-structured interviews
11. Sample coding
12. Excerpts from thematic analysis of participant interviews
13. Steering group comments and rating on Delphi statements
14. Delphi round one statements
15. Invite to participate in expert panel
16. Expert panel demographic and consent form
17. Example of feedback report to panellist
18. Demographics of Delphi expert panel
19. Delphi round one invitation and survey link
20. Delphi round one - statistical summary of results
21. Delphi round one summary report
22. Delphi two - statistical summary of results
23. Delphi round two summary report
24. DAISY swallow screening tool
25. Feasibility study - phase one decision form
26. Feasibility study - phase one decision form
27. DAISY screening tool training video script

NHS
Health Research Authority

NRES Committee London - Stanmore
Ground Floor
NRES/HRA

25 July 2014

Name and address

Dear

Study title:	**Daisy Project: dysphagia following acute cervical spinal cord injury**
REC reference:	**14/LO/1209**
IRAS project ID:	**129588**

Thank you for your letter of 18 July 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 18 July 2014

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Letters of invitation to participant	0.4	18 July 2014
Participant information sheet (PIS)	0.4	18 July 2014

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster]	v0.1	26 May 2014
Interview schedules or topic guides for participants [Participant Interview extended topic guide]	v0.1	23 June 2014
Letter from funder [Letter of intent]	v0.1	12 December 2013
Letters of invitation to participant	0.4	18 July 2014
Non-validated questionnaire [DAISY Project Staff survey]	v0.4	23 June 2014
Other [Staff Survey]	2	10 July 2014
Participant consent form [Participant consent]	v0.1	28 May 2014
Participant information sheet (PIS)	0.4	18 July 2014
REC Application Form [REC_Form_25062014]		25 June 2014
Research protocol or project proposal [Research Protocol]	v.1	23 June 2014
Summary CV for Chief Investigator (CI) [CI CV]	v0.1	23 June 2014
Summary CV for supervisor (student research) [Supervisor CV]	v0.1	24 March 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/LO/1209 **Please quote this number on all correspondence**

Yours sincerely

REC Assistant

E-mail: nrescommittee.

Copy to: R&D

Royal National Orthopaedic Hospital NHS
NHS Trust

R&D Office,

NHS R&D Management Approval Letter for Research falling outside of GAfREC arrangements

To: Jackie McRae

Date: 06/08/2015

Project Title: Development of a screening instrument for dysphagia following acute cervical spinal cord injury: identification of current practice and validation of a tool

R&D ID: 15.016

Sponsor: RNOH

Based on the Governance Arrangements for Research Ethics Committees (GAfREC) as update in 2011, the project does not require Research Ethics Committee review and R&D sign off is adequate for you to proceed with your project.

I am writing on behalf of the Royal National Orthopaedic Hospital NHS Trust Stanmore, to inform you that the above named project has been approved by the Trust and may now proceed.

Conditions of the sign off:

1. All staff involved in the running of this study must adhere to Trust and Research Governance Framework requirements.

2. As Chief/Principal Investigator you are required to formally advise the R&D Office of **ANY** changes to the project including:
   - Any changes to the status of the project, e.g. abandoned, completed etc
   - Any changes to the protocol – however minor.
   - Any changes to the funding arrangements.

3. This sign off is provided for 12 months in the first instance, any further extensions are subject to annual report.

4. Please advice the R&D Office of completion of your project.

Yours sincerely,

Research Management and Governance Lead
Research and Innovation Centre
RNOH

NHS
Health Research Authority

Email: hra.approval@nhs.net

15 June 2016

Ms McRae

Letter of HRA Approval for a study with an existing UK study wide review

Study title:	**Daisy Project: dysphgia following acute cervical spinal chord injury**
IRAS project ID:	**129588**
Sponsor:	**Royal National Orthopaedic Hospital NHS Trust**

Thank you for your request to bring the above referenced study under HRA Approval.

I am pleased to confirm that the study has been given **HRA Approval.** This has been issued on the basis that a study wide review has previously been undertaken, which has confirmed that the study is compliant with the UK wide standards for research in the NHS.

The extension of HRA Approval to this study on this basis allows the sponsor and participating NHS organisations in England to set-up the study in accordance with HRA Approval processes, with decisions on study set-up being taken on the basis of capacity and capability alone.

If you have submitted an amendment to add a new site between 23 March 2016 and the date of this letter, the addition of the new site is also approved.

Participation of NHS Organisations in England

The sponsor should provide a copy of this letter, together with the local document package and a list of the documents provided, to participating NHS organisations in England that are being set up in accordance with HRA Approval Processes. It is for the sponsor to ensure that any documents provided to participating organisations are the current, approved documents.

For non-commercial studies the local document package should include an appropriate Statement of Activities and HRA Schedule of Events. The sponsor should also provide the template agreement to be used in the study, where the sponsor is using an agreement in addition to the Statement of

IRAS project ID	128588

Activities. Participating NHS organisations in England should be aware that the Statement of Activities and HRA Schedule of Events for this study have not been assessed and validated by the HRA. Any changes that are appropriate to the content of the Statement of Activities and HRA Schedule of Events should be agreed in a pragmatic fashion as part of the process of assessing, arranging and confirming capacity and capability to deliver the study.

For commercial studies the local document package should include a validated industry costing template and the template agreement to be used with participating NHS organisations in England.

It is critical that you involve both the research management function (e.g. R&D office and, if the study is on the NIHR portfolio, the LCRN) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

After HRA Approval

In addition to the document, *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC Favourable Opinion, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

IRAS project ID	128588

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/.

If you have any queries about the issue of this letter please, in the first instance, see the further information provided in the question and answer document on the HRA website.

Your IRAS project ID is **129588.** Please quote this on all correspondence.

Yours sincerely

Application Workflow Lead

Email: hra.approval@nhs.net

Copy to: R&D

Version 1: I would like to think that ITU physios should have an opinion and request mouth care for our patients. I also think getting them to consider the benefits of peg vs NG in compromised patients would be useful. I think it is something I would ask but I also think some more junior physios may not feel it is their place to get involved. As there are so many physios though, and in most cases are a source of continuity for the patients, I would say ask them, the responses could be interesting.
It looks pretty good to me, except some minor modifications. D1 Opioids (spelling – tricky word) D2 Another modifier could be: Not meeting nutritional requirements, despite dietetic intervention D3 I would change modifier: NG insitu for over 4-6 weeks
P4. Not everyone would have heard of or considered deflating a tracheostomy cuff.
N3 they will say yes as they deal with the day to day management of them. ?better to ask if they are included in decisions about management. They may also be involved, as they are here, with weaning management. You could almost ask all the questions you put to the physios.
M6 Not all will have heard of vent free breathing, or have considered it as an initial method of weaning, or even a valid weaning method at all. Would be useful to add a question as to whether they know about it in relation to spinal cord injured patients. They will have heard of spontaneous breathing trials, which is used as a pre-extubation test in some ITUs.
Version 2: The 'other' boxes need to be treated as unique answers. Tried to use a few times but was rejected so had to tick inappropriate boxes to get through. Q15 not a good set of responses. Needs an 'other' Q19 'non oral' does that mean enteral or tpn? Or both. Q21 can't remember what was wrong with that. Q31 needs option 'sometimes' we sometimes use speaking valves, Not always and never never. Otherwise quite clever really.
Q10. Add anaesthetist, most ITUs junior docs are such. Q16 my first priority is to make sure they're fit for it. Unfortunately most of those, in our eyes, have equall priority. I would include reducing ventilation pressures and evidence of spontaneous respiratory effort, also to make it possible to include all, some or none as possible answers, rather than have to make one choice only. It will show they're thinking about things. (actually haven't checked to see if I can tick more than one answer. Not clear on instructions) Q17 ditto Q19 interesting to see how long they cap if they do. Q20 change to Ng feeding. Q26 I would put 'no access to salt' next to 'don't refer'
On one of the swallow responses I tried to enter "other" and typed FEES. It wouldn't let me only respond with other and requested an answer. I assume it needed a circle to click on with other?
Otherwise it reads well, only took about 10 mins and I didn't feel like it was repetitive. I filled it in from my phone as well which was convenient.

Appendix 4 Steering group survey comments

DGH/Foundation/Specialist? How about University/ teaching. Some dgh's and specialist are foundation.
If you answered No for question 6 - 'does your ITU admit SCI patients' would the survey then skip to the end?
If you don't select an option for a question but just put comments in 'other' it doesn't allow you to move on without selecting an option from above. Is this so you get a selection from the options you have provided?
It might be covered in other disciplines, but did you want any info on tube selection e.g fenestrated, suction aid, downsize as part of weaning?
There are some occasions where it is yes/no and it may be that you need a 'don't know' option.
Liked the design and flow of questions was logical.

Appendix 5 Final survey questions and response options

Single response (SR), Multiple response (MR), Free Text (FT)

Section 1 Hospital and unit details:	
1. What type of hospital do you work in? • District General Hospital • Major Trauma Centre • Specialist Hospital • Spinal Injury Unit • Teaching Hospital • Other	SR + FT
2. How many beds does the hospital have? • >500 • <500	SR
3. What is the main hospital ICU that you work in? (dropdown selection)	SR + FT
4. Does your intensive care unit have established links with a .. • Major trauma centre • Spinal Injuries Unit • None • Other	SR + FT
5.How many level 3 beds does your intensive care unit have? • <10 • >10	SR
6.Does your intensive care unit admit patients with spinal cord injury? • Yes • No	SR (exclusion question)
7. Does your unit have specific care pathways for managing: ▪ oropharyngeal dysphagia ▪ non-oral nutrition ▪ Patients with paraplegia ▪ Patients with tetraplegia ▪ Ventilator associated pneumonia ▪ Weaning from tracheostomy ▪ Weaning from ventilator ▪ None ▪ Other	MR + FT
8.Which Spinal Outreach Team does your unit have access to? ▪ Duke of Cornwall SCI centre, Salisbury ▪ Golden Jubilee North of England SCI Centre, Middlesbrough ▪ London SCI Centre, Stanmore ▪ Midlands Centre for SCI, Oswestry ▪ National SCI Centre, Stoke Mandeville ▪ North-West SCI Centre, Southport ▪ Princess Royal SCI Centre, Sheffield ▪ Yorkshire Regional SIC, Pinderfields ▪ None ▪ Other	MR + FT
Section 2: Demographic details	
9. What profession are you? • Physiotherapist • Speech and language therapist • Dietitian • Nurse • Doctor	SR
10. What grade are you?/11.What banding are you? • Foundation year 1 • Foundation year 2 • Specialist registrar 1-3 • Specialist registrar 4-6	SR (skip logic)

• Consultant **OR** • Band 5 • Band 6 • Band 7 • Band 8	
12. What is your clinical specialism? ▪ Intensive care ▪ Neurology ▪ Neurosurgery ▪ Orthopaedics ▪ Rehabilitation ▪ Respiratory ▪ Spinal cord injury ▪ Other	MR + FT
Section 3: Ventilator and tracheostomy weaning	
13. Who is regularly involved in your tracheostomy team? ▪ No tracheostomy team ▪ Anaesthetist ▪ Dietitian ▪ ENT doctor ▪ Nurse ▪ Physiotherapist ▪ Speech and language therapist ▪ Other	MR + FT
14. Who determines the weaning programme of ventilated spinal cord injured patients? ▪ ICU Doctor ▪ ICU nurse ▪ Physiotherapist ▪ Respiratory team ▪ Tracheostomy team decisions ▪ Don't know ▪ Other	MR + FT
15. What protocol does the team use for ventilator weaning of patients with cervical spinal cord injury? • Locally agreed protocol • National guidance • Weaning protocol provided by spinal outreach team • Don't know • None • Other	SR + FT
16. What is the first priority when planning a ventilator weaning programme? ▪ Effective communication ▪ Effective secretion management ▪ Maintaining clear chest status ▪ Spontaneous breathing trials ▪ Don't know ▪ Other	MR + FT
17. As part of the ventilator weaning process do you use: ▪ Cuff deflation ▪ Fenestrated tubes ▪ Measures of vital capacity ▪ Speaking valves ▪ Suctionaid tubes ▪ Trache mask ▪ Don't know ▪ Other	MR + FT
18. What do you consider is the impact of an inflated tracheostomy cuff? ▪ Allows safe oral intake ▪ Effective high pressure ventilation ▪ Prevents aspiration of secretions ▪ Prevents cough	MR + FT

▪ Prevents speech ▪ Don't know ▪ Other	
19. Do you routinely block off a tracheostomy before decannulation? • Yes • No • Sometimes • Don't know	SR
Section 4: Feeding	
20. What criteria does your unit use for commencing non-oral feeding in a spinal cord injured patient? ▪ Inability to be positioned upright ▪ Infection ▪ Prolonged intubation ▪ Prolonged sedation ▪ Tracheostomy in situ ▪ Unable to meet nutritional requirements through oral intake ▪ Don't know ▪ Other	MR + FT
21. What will determine the change from a nasogastric tube to a gastrostomy feeding tube? ▪ Increased nutritional need ▪ Infection risk ▪ NG insitu for over 4-6 weeks ▪ Ongoing swalloinwg problems ▪ Patient discomfort ▪ Recommendation by dietitian ▪ Recommendation by SLT ▪ Repeated displacement ▪ To assist hospital transfer ▪ Don't know ▪ Other	MR + FT
22. When do you consider a cervical spinal cord injured patient is ready to start eating? ▪ After tracheostomy decannulation ▪ After weaning from ventilator ▪ At the patient's request ▪ Following swallowing assessment ▪ When they are able to talk ▪ When sitting upright ▪ When the tracheostomy cuff is deflated ▪ When NGT comes out ▪ Don't know ▪ Other	MR + FT
Section 5: Swallowing	
23. Who screens for swallowing problems on the intensive care unit? ▪ Dietitian ▪ Doctor ▪ Nurse ▪ Physiotherapist ▪ Speech and language therapist ▪ No swallow screening	MR
24. How are swallowing problems determined on ICU? ▪ Patient's ability to speak ▪ Patient's ability to swallow saliva ▪ Patient's ability to swallow thickened fluids ▪ Patient's ability to swallow water ▪ Patient's ability to swallow yoghurt ▪ Test of aspiration using blue dye ▪ Don't know ▪ Other	MR + FT
25. What clinical signs do you consider are evidence of swallowing problems in patients with a cervical spinal cord injury? ▪ Chest infection ▪ Coughing or choking after food or fluid	MR + FT

▪ Dropping oxygen saturations ▪ Food being suctioned from trache ▪ Food residue in the mouth ▪ Not expected to experience swallowing problems ▪ Patient complaint of pain in the throat ▪ Patient complaint of swallowing problems ▪ Spiking pyrexia ▪ Wet voice ▪ Other	
26. What are the criteria for referring to Speech and Language Therapy? ▪ Ability to sit upright ▪ After decannulation ▪ Aspiration pneumonia ▪ Positive result from swallow screen ▪ Refer for communication problems only ▪ Routine Speech and Language Therapy involvement on ICU ▪ Tracheostomy cuff deflation ▪ No Speech and Language Therapy involvement on ICU ▪ Other	MR + FT
27. What swallowing assessment/s does the Speech & Language Therapist routinely use for patients on ICU? ▪ Bedside swallow assessment ▪ Flexible endoscopic evaluation of swallowing (FEES) ▪ Flexible nasendoscopy by ENT ▪ Videofluoroscopy ▪ None ▪ Don't know	MR
28. Do you consider it safe to allow a patient to eat and drink whilst they have the cuff inflated on their tracheostomy tube? • Yes • No • Sometimes • Don't know • Other	SR + FT
Section 6: Mouthcare	
29. Are you involved in the delivery of mouthcare? • Yes • no If yes → 31	SR (skip logic)
30. Who is responsible for oral hygiene on your unit? • Nurse • Don't know • Other	SR + FT
31. How is the frequency of oral care determined? • Daily assessment using a mouthcare tool • Mouthcare provided at patient's request • Twice daily mouthcare provided as standard • Other	SR +FT
32. Do you advise on the following aspects of oral hygiene? ▪ Choice of cleaning or moisturising products ▪ Choice of mouthcare tools ▪ Frequency of mouthcare ▪ Technique for effective mouthcare ▪ Use of an oral hygiene protocol ▪ No ▪ Other	MR + FT
Section 7: Communication	
33. How do you support patients with a tracheostomy and cervical spinal cord injury who cannot speak in ICU? ▪ Advice to patient, family and staff ▪ Encourage mouthing ▪ Low technology non-electronic aids	MR + FT

▪ High technology electronic communication aids ▪ No special support ▪ Don't know ▪ Other	
34. Is cuff deflation considered a communication option for ventilator dependent patients? • Yes • No • Sometimes • Don't know	SR
35. Do you use in-line speaking valves with ventilator dependent patients? ▪ Yes, always ▪ Yes, only after flexible nasendoscopy airway assessment ▪ Yes, sometimes ▪ No ▪ Other	MR + FT
Section 8: Comments	
36. Do you have any other comments you would like to add about the clinical management of cervical spinal cord injured patients?	FT (optional)
37. If you would like to be involved in a future aspect of the study to develop a screening tool, please add your email address:	FT (optional)

Participant Information Sheet
DAISY Project: Dysphagia following acute cervical spinal cord injury
Staff Survey

Dear colleague,

You have been selected to take part in an online survey as a health professional working in an acute or critical care unit in England, that admits people following a cervical spinal cord injury. Research in this area is currently very limited, so your contribution will add to the international body of evidence.

The survey aims to look at the clinical pathways for cervical spinal cord injury management and how clinical decisions are made by different team members. The questions are multiple choice and are slightly different for each professional to reflect varied roles within the team. We would like to hear from nurses, doctors, dieticians, physiotherapists and speech and language therapists. The topics deal with respiratory, nutritional and swallow management. This is part of a larger project examining how swallowing problems are identified, with an aim to creating a valid screening tool.

The survey is available online through SurveyMonkey and can be navigated easily by using the function buttons on the screen. The responses are anonymous and stored within SurveyMonkey in a secure environment. Details of identifying Trusts are confidential and will be excluded in data analysis. They are collected only to monitor distribution.
This survey should take about 10 minutes of your time as the questions are multiple choice with the option of adding your own comment. You can go back to the previous screen but you cannot save the responses as you proceed. The survey will end if you answer that your unit does not take spinal cord injury patients.

The data will be reviewed for trends in clinical practice. The results will be disseminated through your professional networks, presented at national and international meetings and published in a peer reviewed journal. The information will also be used for a future stage of the study to develop components of the swallow screening tool.

The study has been funded by the National Institute for Health Research as part of the Clinical Doctoral Research Fellowship awarded to Jackie McRae. The project is supported by University College London and the Royal National Orthopaedic Hospital Trust.

We are very keen to have representation from the spectrum of team members and would be grateful for your individual contribution. For more information go to www.daisyproject.info and click on the survey link, alternatively you can go direct to the survey:

https://www.surveymonkey.com/s/daisyproject

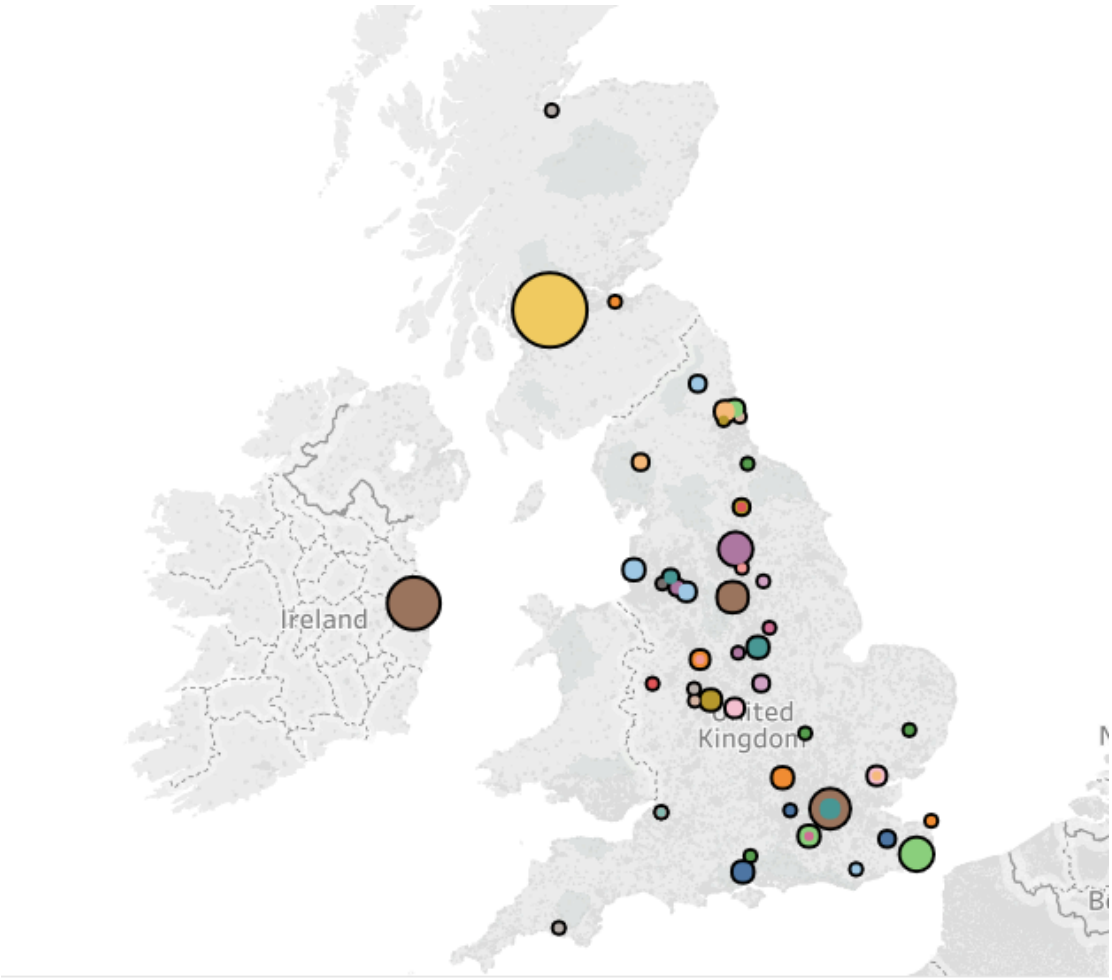
For any queries about the study you can contact Jackie McRae at info@daisyproject.info

For questions about participating in research, please contact the [redacted]

Yours sincerely

Jackie McRae

Appendix 7 Heatmap of survey respondents across United Kingdom



Appendix 8 Survey responses across specialised and non-specialised hospitals

Question	Response options	Hospital Units			P value
		Non-specialised (n=178)	Specialised (n=41)	Missing n (%)	
Hospital bed no. n=219	>500	135 (88.8)	17 (11.2)	0	<.001*
	<500	43 (64.2)	24 (35.8)		
Level 3 bed no. n=213	>10	115 (89.1)	14 (10.9)	3%	.001*
	<10	60 (71.4)	24 (28.6)		
Links with other units n=219	MTC	96 (53.9)	10 (24.4)	0	.008*
	SIU	55 (30.9)	22 (53.7)		
	None	19 (10.7)	6 (14.6)		
	Other	8 (4.5)	3 (7.3)		
Unit admission for SCI patients n=213	yes	152 (86.9)	30 (78.9)	3%	.210
	no	23 (13.1)	8 (21.1)		
Care pathways n=166	VAP	102 (74.5)	14 (48.3)	24%	.005*
	Non-oral nutrition	97 (70.8)	17 (58.6)		.199
	Ventilator weaning	80 (58.4)	22 (75.9)		.079
	Tracheostomy weaning	75 (54.7)	19 (65.5)		.288
	Dysphagia	58 (42.3)	11 (37.9)		.662
	Tetraplegia	53 (38.7)	19 (65.5)		.008*
	Paraplegia	47 (34.3)	19 (65.5)		.002*
	None	8 (5.8)	0 (0)		.456
Access to Spinal Outreach Team n=164	LSCIC, Stanmore	37 (27.0)	12 (41.4)	0	.123
	NSCIC, Stoke Mandeville	33 (24.1)	4 (13.8)		.226
	Princess Royal, Sheffield	26 (19.0)	1 (3.4)		.040*
	SCIC, Middlesborough	20 (14.6)	0 (0)		.028*
	Midlands, Oswestry	14 (10.2)	1 (3.4)		.248
	North West, Southport	11 (8.0)	3 (10.3)		.684
	Duke of Cornwall, Salisbury	9 (6.6)	5 (17.2)		.060
	Yorkshire, Pinderfields	4 (2.9)	1 (3.4)		.880
	None	5 (3.6)	2 (6.9)		.429
	Other	8 (5.8)	3 (10.7)		.376
DEMOGRAPHICS					
		Non-specialised	**Specialised**		
Profession n=166	Nurse	48 (35.0)	7 (24.1)	24%	.058
	Doctor	46 (33.6)	7 (24.1)		
	PT	18 (13.1)	9 (31.0)		
	SLT	17 (12.4)	6 (20.7)		
	Dietitian	8 (5.8)	0 (0)		
Doctor Grade/ Nurse/AHP band n=166	Consultant	44 (95.6)	7 (100.0)	24%	.751
	Specialist registrar	2 (4.4)	0 (0)		
	Band 5	2 (2.2)	0 (0)		.768
	Band 6	22 (24.2)	7 (33.3)		
	Band 7	47 (51.6)	10 (47.6)		
	Band 8	20 (22.0)	4 (19.0)		
Clinical specialism^ n=164	Intensive Care	114 (83.8)	9 (32.1)	25%	<.001*
	SCI	10 (7.4)	16 (57.1)		<.001*
	Neurosurgery	17 (12.5)	5 (17.9)		.449
	Respiratory	13 (9.6)	4 (14.3)		.455
	Neurology	13 (9.6)	4 (14.3)		.455
	Rehabilitation	5 (3.7)	10 (35.7)		<.001*

Appendix 8 Survey responses across specialised and non-specialised hospitals

	Orthopaedics	1 (0.7)	1 (3.6)		.213
	Other	12 (8.8)	0(0)		.103
RESPIRATORY MANAGEMENT					
		Non-specialised	**Specialised**		
Tracheostomy team members^ n=152	Nurse	68 (54.4)	15 (55.6)	31%	.913
	PT	59 (47.2)	20 (74.1)		.011*
	SLT	55 (44.0)	17 (65.4)		.047*
	Anaesthetist	53 (42.4)	15 (55.6)		.212
	No trache team	40 (32.0)	5 (18.5)		.164
	ENT	27 (21.6)	4 (14.8)		.427
	Dietitian	9 (7.2)	5 (18.5)		.065
	Other	12 (9.7)	2 (7.4)		.712
Lead for vent weaning^ n=152	ICU doctor	108 (86.4)	9 (33.3)	31%	<.001*
	PT	53 (42.4)	7 (25.9)		.106
	ICU nurse	31 (24.8)	4 (14.8)		.256
	Tracheostomy team	13 (10.4)	13 (48.1)		<.001*
	Respiratory team	4 (3.2)	8 (29.6)		<.001*
	Other	11 (8.8)	4 (14.8)		.349
	Don't know	3 (2.4)	0 (0)		.414
Ventilator weaning protocol n=152	Locally agreed protocol	52 (41.6)	12 (44.4)	31%	.231
	Spinal outreach team protocol	23 (18.4)	7 (25.9)		
	National guidance	7 (5.6)	4 (14.8)		
	Don't know	25 (20.0)	2 (7.4)		
	None	15 (12.0)	1 (3.7)		
	Other	3 (2.4)	1 (3.7)		
First priority for ventilator weaning^ n=151	Effective communication	42 (84.0)	8 (16.0)	31%	.690
	Spontaneous breathing	36 (76.6)	11 (23.4)		.223
	Clear chest	32 (71.1)	13 (28.9)		.021
	Effective secretion management	34 (79.1)	9 (20.9)		.521
	Don't know	20 (95.2)	1 (4.8)		.093
	Other	14 (87.5)	2 (12.5)		.560
Ventilator weaning process^ n=150	Cuff deflation	103 (82.4)	25 (96.2)	31%	.076
	Speaking valve	96 (76.8)	23 (88.5)		.186
	Trache mask	85 (68.0)	15 (57.7)		.312
	Vital capacity	51 (40.8)	23 (88.5)		<.001*
	Fenestrated tube	46 (36.8)	9 (34.6)		.833
	Suctionaid	43 (34.4)	10 (38.5)		.693
	Don't know	8 6.4)	0 (0)		.185
	Other	6 (4.8)	4 (15.4)		.048
Impact of inflated cuff^ n=150	Prevents speech	95 (76.6)	20 (76.9)	31%	.973
	Effective high pressure ventilation	87 (70.2)	16 (61.5)		.389
	Aspiration prevention	70 (56.5)	16 (61.5)		.633
	Cough prevention	16 (12.9)	9 (34.6)		.007*
	Safe oral intake	16 (12.9)	2 (7.7)		.457
	Don't know	5 (4.0)	0 (0)		.298
	Other	6 (4.8)	0 (0)		.252
Routine capping n=150	No	61 (49.2)	2 (7.7)	31%	<.001*
	Yes	21 (16.9)	20 (76.9)		
	Sometimes	34 (27.4)	4 (15.4)		

Appendix 8 Survey responses across specialised and non-specialised hospitals

	Don't know	8 (6.5)	0 (0)		
NUTRITION					
		Non-specialised	**Specialised**		
Non-oral feeding criteria^ n=144	Unable to meet nutritional requirements orally	96 (81.4)	23 (88.5)	34%	.387
	Prolonged intubation	61 (51.7)	12 (46.2)		.609
	Prolonged sedation	57 (48.3)	12 (46.2)		.842
	Tracheostomy in situ	33 (28.0)	1 (3.8)		.009*
	Can't sit upright	15 (12.7)	4 (15.4)		.715
	Infection	8 (6.8)	2 (7.7)		.868
	Don't know	6 (5.1)	1 (3.8)		.790
	Other	7 (5.9)	3 (11.5)		.309
NGT to PEG^ n=144	Ongoing swallowing problems	87 (73.7)	21 (80.8)	34%	.453
	SLT recommendation	69 (58.5)	22 (84.6)		.012*
	NG in-situ 4-6 weeks	58 (49.2)	16 (61.5)		.253
	Dietitian recommendation	52 (44.1)	21 (80.8)		.001*
	Patient discomfort	35 (29.7)	10 (38.5)		.381
	Repeated displacement	37 (31.4)	8 (30.8)		.953
	Assist hospital transfer	23 (19.5)	3 (11.5)		.340
	Increased nutritional need	7 (5.9)	1 (3.8)		.674
	Infection risk	4 (3.4)	2 (7.7)		.320
	Don't know	9 (7.6)	1 (3.8)		.492
	Other	6 (5.1)	3 (11.5)		.218
Ready to start eating^ n=144	After swallow assessment	101 (85.6)	25 (96.2)	34%	.141
	Trache cuff deflated	30 (25.4)	7 (26.9)		.874
	Sitting upright	21 (17.8)	4 (15.4)		.769
	After ventilator weaning	16 (13.6)	1 (3.8)		.165
	When able to talk	12 (10.2)	4 (15.4)		.444
	At patient request	9 (7.6)	0 (0)		.146
	After decannulation	6 (5.1)	1 (3.8)		.790
	When NG removed	1 (0.8)	0 (0)		.638
	Don't know	6 (5.1)	0 (0)		.240
	Other	6 (5.1)	2 (7.7)		.599
SWALLOWING					
		Non-specialised	**Specialised**		
Screening for swallowing^ n=144	SLT	100 (84.7)	25 (96.2)	34%	.120
	Nurse	68 (57.6)	10 (38.5)		.076
	Doctor	24 (20.3)	4 (15.4)		.563
	PT	21 (17.8)	1 (3.8)		.073
	No screening	6 (5.1)	2 (7.7)		.599
	Dietitian	4 (3.4)	0 (0)		.341
Screening methods^ n=144	Saliva	71 (60.2)	17 (65.4)	34%	.621
	Water	73 (61.9)	14 (53.8)		.449
	Thickened fluids	52 (44.1)	8 (30.8)		.213
	Blue dye	51 (43.2)	8 (30.8)		.243
	Yoghurt	44 (37.3)	10 (38.5)		.911
	Speaking	27 (22.9)	5 (19.2)		.685
	Other	17 (14.4)	5 (19.2)		.536
	Don't know	4 (3.4)	3 (11.5)		.080
Clinical signs	Coughing or choking	110(94.8)	25 (96.2)	35%	.778

Appendix 8 Survey responses across specialised and non-specialised hospitals

of dysphagia^ n=142	Food suctioned from tracheostomy	104 (89.7)	26 (100.0)		.087
	Aspiration pneumonia	102 (87.9)	26 (100.0)		.062
	Patient complaint of dysphagia	83 (71.6)	21 (80.8)		.337
	Wet voice	69 (59.5)	21 (80.8)		.042*
	Intra-oral food residue	70 (60.3)	18 (69.2)		.399
	Dropping O_2 saturations	68 (58.6)	19 (73.1)		.171
	Spiking pyrexia	35 (30.2)	14 (53.8)		.022*
	Patient complaint of throat pain	18 (15.5)	8 (30.8)		.069
	Dysphagia not expected	3 (2.6)	1 (3.8)		.726
	Other	6 (5.2)	0 (0)		.236
Criteria for SLT referral^ n=142	Routine SLT	66 (56.9)	16 (61.5)	35%	.665
	Positive result from swallow screen	37 (31.9)	8 (30.8)		.911
	Tracheostomy cuff deflation	24 (20.7)	4 (15.4)		.539
	Aspiration pneumonia	16 (3.8)	9 (34.6)		.012*
	Ability to sit upright	9 (7.8)	4 (15.4)		.223
	Swallow problem	8 (6.9)	2 (7.7)		.886
	After decannulation	8 (6.9)	0 (0)		.168
	No ICU SLT involvement	7 (6.0)	0 (0)		.199
	Refer for communication problems only	5 (4.3)	1 (3.8)		.915
	Other	11 (9.5)	3 (11.5)		.751
Dysphagia assessment^ n=142	BSE	99 (85.3)	23 (88.5)	35%	.680
	FEES	37 (31.9)	14 (53.8)		.035*
	VFS	29 (25.0)	2 (46.2)		.031*
	ENT Flexible nasendoscopy	9 (7.8)	2 (7.7)		.991
	Don't know	9 (7.8)	0 (0)		.142
	None	2 (1.7)	0 (0)		.500
Eat and drink with cuff inflated n=142	Sometimes	64 (55.2)	11 (42.0)	35%	.032*
	No	22 (19.0)	12 (46.2)		
	Yes	18 (15.5)	0 (0)		
	Don't know	5 (4.3)	2 (7.7)		
	Other	7 (6.0)	1 (4.0)		
MOUTHCARE					
		Non-specialised	**Specialised**		
Delivery of mouthcare n=142	Yes	62 (53.4)	10 (38.5)	35%	.167
Responsible for oral hygiene n=142	Nurse	52 (96.3)	15 (100.0)	35%	.449
	Don't know	2 (3.7)	0 (0)		
Frequency of oral care n=142	Daily assessment with tool	43 (37.1)	9 (34.6)	35%	.792
	Twice daily mouthcare	40 (34.5)	8 (30.8)		
	Mouthcare on request	2 (1.7)	0 (0)		
	Other	31 (26.7)	9 (34.6)		
Oral hygiene advise^ n=141	No advice given	53 (45.7)	11 (42.3)	36%	.754
	Frequency	43 (37.1)	8 (30.8)		.545
	Cleaning products	31 (26.7)	8 (30.8)		.676
	Oral hygiene protocol	30 (25.9)	8 (30.8)		.609
	Effective technique	28 (24.1)	8 (30.8)		.482
	Mouthcare tools	19 (16.4)	5 (19.2)		.726
	Other				

Appendix 8 Survey responses across specialised and non-specialised hospitals

Communication					
		Non-specialised	**Specialised**		
Communication options^ n=141	Low technology aids	99 (86.1)	21 (80.8)	36%	.492
	Advice to patients and family	97 (84.3)	22 (84.6)		.973
	Encourage mouthing	88 (76.5)	22 (84.6)		.368
	High technology aids	48 (41.7)	9 (34.6)		.504
	No special support	2 (1.7)	0 (0)		.498
	Don't know	5 (4.3)	1 (3.8)		.909
	Other	6 (5.2)	2 (7.7)		.622
Cuff down for speech n=141	Yes	51 (44.3)	18 (69.2)	36%	.080
	Sometimes	44 (38.3)	4 (15.4)		
	No	10 (8.7)	3 (11.5)		
	Don't know	10 (8.7)	1 (3.8)		
Speaking valves^ n=141	Sometimes	66 (57.4)	14 (53.8)	36%	.742
	No	27 (23.5)	3 (11.5)		.179
	Always	15 (13.0)	6 (23.1)		.194
	After nasendoscopy	0 (0)	1 (3.8)		.035*
	Other	8 (7.0)	1 (3.8)		.558
^ percentages may add up to more than 100% because of multiple responses *** p value less than 0.05 using Chi-Square test of association**					

Question	Response options	Doctor	Nurse	PT	SLT	Dietitian	P value (Fisher's
DEMOGRAPHIC DETAILS							
	Profession n=166	53 (31.9)	55 (33.1)	27 (16.3)	23 (13.9)	8 (4.8)	
Hospital bed no. n=219	>500	38 (71.7)	39 (70.9)	21 (77.8)	12 (52.2)	7 (87.5)	.281
	<500	15 (28.3)	16 (29.1)	6 (22.2)	11 (47.8)	1 (12.5)	
Level 3 bed no. n=213	>10	36 (67.9)	31 (56.4)	19 (70.4)	16 (69.6)	5 (62.5)	.654
	<10	17 (32.1)	24 (43.6)	8 (29.6)	7 (30.4)	3 (37.5)	
Unit admission for SCI patients n=213	Yes	53 (100.0)	53 (96.4)	27 (100.0)	23 (100.0)	8 (100.0)	-
Doctor Grade/ Nurse/AHP band n=166	Consultant	51 (96.2)	-	-	-	-	-
	Specialist registrar	2 (3.8)	-	-	-	-	
	Band 5		2 (3.6)	0 (0)	0 (0)	0 (0)	.154
	Band 6		20 (36.4)	5 (19.2)	2 (8.7)	2 (25.0)	
	Band 7	-	26 (47.3)	13 (50.0)	14 (60.9)	4 (50.0)	
	Band 8	-	7 (12.7)	8 (30.8)	7 (30.4)	2 (25.0)	
Clinical specialism^ n=164	Intensive Care	44 (77.2)	48 (72.7)	9 (22.0)	15 (25.4)	7 (63.6)	<.001
	SCI	4 (7.0)	5 (7.6)	9 (22.0)	7 (11.9)	1 (9.1)	.005
	Neurosurgery	1 (1.8)	4 (6.1)	6 (14.6)	10 (16.9)	1 (9.1)	<.001
	Respiratory	0 (0)	2 (3.0)	11 (26.8)	4 (6.8)	0 (0)	<.001
	Neurology	0 (0)	1 (1.5)	4 (9.8)	12 (20.3)	0 (0)	<.001
	Rehabilitation	5 (8.8)	3 (4.5)	2 (4.9)	5 (8.5)	0 (0)	.258
	Orthopaedics	0 (0)	1 (1.5)	0 (0)	1 (1.7)	0 (0)	.368
	Other	3 (5.3)	2 (3.0)	0(0)	5 (8.5)	2 (18.2)	.009

Question	Response options	Doctor	Nurse	PT	SLT	Dietitian	P value (Fisher's
RESPIRATORY MANAGMENT							
Tracheostomy team members^ n=152	Nurse	26 (24.3)	29 (21.5)	13 (17.2)	10 (15.2)	5 (22.7)	.827
	PT	20 (18.7)	21 (15.6)	19 (21.0)	15 (22.7)	4 (18.2)	.019*
	SLT	14 (13.1)	22 (16.3)	15 (19.7)	16 (24.2)	5 (22.7)	.003*
	Anaesthetist	22 (20.6)	22 (16.3)	12 (15.8)	10 (15.2)	2 (9.1)	.877
	No trache team	14 (13.1)	19 (14.1)	7 (9.2)	3 (4.5)	2 (9.1)	.319
	ENT	6 (5.6)	11 (8.1)	6 (7.9)	5 (7.6)	3 (13.6)	.349
	Dietitian	1 (0.9)	9 (6.7)	2 (2.6)	2 (3.0)	0 (0)	.059
	Other	4 (3.7)	2 (1.5)	2 (2.6)	5 (7.6)	1 (4.5)	.133
Lead for vent weaning^ n=152	ICU doctor	39 (48.8)	40 (43.5)	15 (34.9)	16 (42.1)	7 (46.7)	.151
	PT	18 (22.5)	15 (16.3)	18 (41.9)	5 (13.2)	4 (26.7)	.009
	ICU nurse	9 (11.3)	22 (23.9)	1 (2.3)	2 (5.3)	1 (6.7)	<.001
	Tracheostomy team	6 (7.5)	4 (4.3)	4 (9.3)	11 (28.9)	1 (6.7)	.001
	Respiratory team	3 (3.8)	4 (4.3)	2 (4.7)	2 (5.3)	1 (6.7)	.878
	Other	5 (6.3)	5 (5.4)	3 (7.0)	2 (5.3)	0 (0)	.095
	Don't know	0 (0)	2 (2.2)	0 (0)	0 (0)	1 (6.7)	1.00
Ventilator weaning protocol n=152	Locally agreed protocol	25 (51.0)	21 (43.8)	11 (42.3)	6 (28.6)	1 (12.5)	-
	Spinal outreach team protocol	11 (22.4)	8 (16.7)	6 (23.1)	5 (23.8)	0 (0)	
	National guidance	4 (8.2)	1 (2.1)	5 (19.2)	1 (4.8)	0 (0)	
	Don't know	2 (4.1)	10 (20.8)	1 (3.8)	8 (38.1)	6 (75.0)	
	None	6 (12.2)	6 (12.5)	3 (11.5)	1 (4.8)	0 (0)	
	Other	1 (2.0)	2 (4.2)	0 (0)	0 (0)	1 (12.5)	
First priority for ventilator weaning^ n=151	Effective communication	20 (40.8)	18 (37.5)	7 (26.9)	4 (19.0)	1 (12.5)	.258
	Spontaneous breathing	14 (28.6)	20 (41.7)	6 (23.1)	6 (28.6)	1 (12.5)	.361
	Clear chest	10 (20.4)	15 (31.9)	13 (50.0)	6 (28.6)	1 (12.5)	.090
	Effective secretion management	14 (28.6)	16 (33.3)	9 (34.6)	3 (14.3)	1 (12.5)	.421
	Don't know	5 (10.2)	2 (4.2)	0 (0)	7 (33.3)	7 (87.5)	<.001*

	Other	8 (16.3)	6 (12.5)	1 (3.8)	1 (4.8)	0 (0)	.419
Ventilator weaning process^ n=150	Cuff deflation	45 (23.8)	38 (25.7)	24 (23.1)	19 (21.3)	2 (11.8)	.001
	Speaking valve	42 (22.2)	34 (23.0)	22 (21.2)	18 (20.2)	3 (17.6)	.038
	Trache mask	32 (16.9)	30 (20.3)	18 (17.3)	18 (20.2)	2 (11.8)	.047
	Vital capacity	24 (12.7)	13 (8.8)	21 (20.2)	14 (15.7)	2 (11.8)	<.001
	Fenestrated tube	24 (12.7)	18 (12.2)	7 (6.7)	5 (5.6)	1 (5.9)	.107
	Suctionaid	19 (10.1)	12 (8.1)	9 (8.7)	11 (12.4)	2 (11.8)	.295
	Don't know	0 (0)	2 (1.4)	0 (0)	2 (2.2)	4 (23.5)	<.001
	Other	3 (1.6)	1 (0.7)	3 (2.9)	2 (2.2)	1 (5.9)	.323
Impact of inflated cuff^ n=150	Prevents speech	39 (34.2)	36 (30.0)	21 (33.9)	17 (33.3)	2 (18.2)	.032*
	Effective high pressure ventilation	36 (31.6)	28 (23.3)	18 (29.0)	18 (35.3)	3 (27.3)	.083
	Aspiration prevention	27 (23.7)	37 (30.8)	15 (24.2)	5 (9.8)	2 (18.2)	<.001*
	Cough prevention	5 (4.4)	6 (5.0)	5 (8.1)	9 (17.6)	0 (0)	.016*
	Safe oral intake	6 (5.3)	11 (9.2)	1 (1.6)	0 (0)	0 (0)	.026*
	Don't know	0 (0)	1 (0.8)	0 (0)	0 (0)	4 (36.4)	<.001*
	Other	1 (0.9)	1 (0.8)	2 (3.2)	2 (3.9)	0 (0)	.382
Routine capping n=150	No	26 (53.1)	22 (47.8)	7 (26.9)	7 (33.3)	1 (12.5)	<.001
	Yes	13 (26.5)	8 (17.4)	13 (50.0)	7 (33.3)	0 (0)	
	Sometimes	10 (20.4)	15 (32.6)	6 (23.1)	7 (33.3)	0 (0)	
	Don't know	0 (0)	1 (2.2)	0 (0)	0 (0)	7 (87.5)	

Question	Response options	Doctor	Nurse	PT	SLT	Dietitian	P value (Fisher's
NUTRITION							
Non-oral feeding criteria^ n=144	Unable to meet nutritional requirements orally	40 (42.1)	35 (31.8)	20 (35.1)	17 (30.9)	7 (29.2)	.890
	Prolonged intubation	18 (18.9)	24 (21.8)	12 (21.1)	13 (23.6)	6 (25.0)	.084
	Prolonged sedation	17 (17.9)	21 (19.1)	9 (15.8)	16 (29.1)	6 (25.0)	.001*
	Tracheostomy in situ	9 (9.5)	14 (12.7)	4 (7.0)	2 (3.6)	5 (20.8)	.025*
	Can't sit upright	2 (2.1)	10 (9.1)	3 (5.3)	4 (7.3)	0 (0)	.042*
	Infection	3 (3.2)	3 (2.7)	2 (3.5)	2 (3.6)	0 (0)	.964
	Don't know	2 (2.1)	2 (1.8)	3 (5.3)	0 (0)	0 (0)	.563
	Other	4 (4.2)	1 (0.9)	4 (7.0)	1 (1.8)	0 (0)	.314
NGT to PEG^ n=144	Ongoing swallowing problems	34 (23.0)	33 (23.7)	18 (21.4)	16 (18.2)	7 (19.4)	.698
	SLT recommendation	22 (14.9)	27 (19.4)	21 (25.0)	17 (19.3)	4 (11.1)	.002*
	NG in-situ 4-6 weeks	20 (13.5)	26 (18.7)	10 (11.9)	11 (12.5)	7 (19.4)	.051
	Dietitian recommendation	17 (11.5)	22 (15.8)	14 (16.7)	15 (17.0)	5 (13.9)	.023*
	Patient discomfort	17 (11.5)	11 (7.9)	5 (6.0)	8 (9.1)	4 (11.1)	.265
	Repeated displacement	17 (11.5)	10 (7.2)	4 (4.8)	10 (11.4)	4 (11.1)	.036*
	Assist hospital transfer	9 (6.1)	2 (1.4)	7 (8.3)	5 (5.7)	3 (8.3)	.021*
	Increased nutritional need	1 (0.7)	3 (2.2)	0 (0)	3 (3.4)	1 (2.8)	.078
	Infection risk	2 (1.4)	2 (1.4)	0 (0)	1 (1.1)	1 (2.8)	.484
	Don't know	4 (2.7)	2 (1.4)	4 (4.8)	0 (0)	0 (0)	.344
	Other	5 (3.4)	1 (0.7)	1 (1.2)	2 (2.3)	0 (0)	.450
Ready to start eating^ n=144	After swallow assessment	40 (83.3)	38 (88.4)	23 (88.5)	17 (89.5)	8 (100.0)	.866
	Trache cuff deflated	7 (14.6)	15 (34.9)	9 (34.6)	5 (26.3)	1 (12.5)	.136
	Sitting upright	4 (8.3)	11 (25.6)	6 (23.1)	3 (15.8)	1 (12.5)	.210
	After ventilator weaning	5 (10.4)	5 (11.6)	5 (19.2)	1 (5.3)	1 (12.5)	.693
	When able to talk	10 (20.8)	3 (7.0)	1 (3.8)	1 (5.3)	1 (12.5)	.140
	At patient request	4 (8.3)	1 (2.3)	1 (3.8)	2 (10.5)	1 (12.5)	.416
	After decannulation	2 (4.2)	2 (4.7)	1 (3.8)	1 (5.3)	1 (12.5)	.736

	When NG removed	0 (0)	0 (0)	0 (0)	0 (0)	1 (12.5)	.056
	Don't know	1 (2.1)	4 (9.3)	1 (3.8)	0 (0)	0 (0)	.456
	Other	2 (4.2)	2 (4.7)	3 (11.5)	1 (5.3)	0 (0)	.722

Question	Response options	Doctor	Nurse	PT	SLT	Dietitian	P value (Fisher's
Swallowing							
Screening for swallowing^ n=144	SLT	43 (46.2)	43 (52.4)	22 (53.7)	12 (35.3)	5 (33.3)	<.001*
	Nurse	24 (25.8)	26 (31.7)	11 (26.8)	11 (32.4)	6 (40.0)	.428
	Doctor	14 (15.1)	7 (8.5)	1 (2.4)	4 (11.8)	2 (13.3)	.080
	PT	9 (9.7)	4 (4.9)	4 (9.8)	3 (8.8)	2 (13.3)	.614
	No screening	1 (1.1)	1 (1.2)	3 (7.3)	3 (8.8)	0 (0)	.092
	Dietitian	2 (2.2)	1 (1.2)	0 (0)	1 (2.9)	0 (0)	.742
Screening methods^ n=144	Saliva	44 (20.5)	17 (19.3)	10 (18.9)	14 (23.7)	3 (20.0)	.009*
	Water	45 (20.9)	19 (21.6)	9 (17.0)	11 (18.6)	3 (20.0)	.364
	Thickened fluids	29 (13.5)	14 (15.9)	9 (17.0)	6 (10.2)	2 (13.3)	<.001*
	Blue dye	28 (13.0)	15 (17.0)	8 (15.1)	7 (11.9)	1 (6.7)	<.001*
	Yoghurt	29 (13.5)	9 (10.2)	6 (11.3)	8 (13.6)	2 (13.3)	.274
	Speaking	18 (8.4)	5 (5.7)	4 (7.5)	5 (8.5)	0 (0)	.326
	Other	8 (3.7)	6 (6.8)	3 (5.7)	3 (5.1)	0 (0)	.842
	Don't know	2 (0.9)	0 (0)	2 (3.8)	3 (5.1)	0 (0)	.236
Clinical signs of dysphagia^ n=142	Coughing or choking	46 (18.0)	41 (16.6)	24 (15.1)	17 (12.4)	7 (14.6)	.368
	Food suctioned from tracheostomy	45 (17.6)	37 (15.0)	23 (14.5)	18 (13.1)	7 (14.6)	.786
	Aspiration pneumonia	40 (15.6)	38 (15.4)	24 (15.1)	19 (13.9)	7 (14.6)	.227
	Patient complaint of dysphagia	32 (12.5)	29 (11.7)	20 (12.6)	18 (13.1)	5 (10.4)	.100
	Wet voice	17 (6.6)	26 (10.5)	25 (15.7)	16 (11.7)	6 (12.5)	<.001*
	Intra-oral food residue	30 (11.7)	27 (10.9)	11 (6.9)	15 (10.9)	5 (10.4)	.218
	Dropping O_2 saturations	24 (9.4)	29 (11.7)	16 (10.1)	11 (8.0)	7 (14.6)	.204
	Spiking pyrexia	9 (3.5)	12 (4.9)	11 (6.9)	14 (10.2)	3 (6.3)	<.001*
	Patient complaint of throat pain	9 (3.5)	7 (2.8)	3 (1.9)	7 (5.1)	0 (0)	.196
	Dysphagia not expected	3 (1.2)	0 (0)	0 (0)	1 (0.7)	0 (0)	.329
	Other	1 (0.4)	1 (0.4)	2 (1.3)	1 (0.7)	1 (2.1)	.286
Criteria for SLT referral^ n=142	Routine SLT	29 (41.4)	29(39.2)	9 (22.5)	13 (36.1)	2 (11.1)	.022*
	Positive result from swallow screen	16 (22.9)	10 (13.5)	10 (25.0)	4 (11.1)	5 (27.8)	.173

	Tracheostomy cuff deflation	4 (5.7)	8 (10.8)	9 (22.5)	3 (8.3)	4 (22.2)	.011*
	Aspiration pneumonia	8 (11.4)	7 (9.5)	3 (7.5)	6 (16.7)	1 (5.6)	.555
	Ability to sit upright	1 (1.4)	5 (6.8)	3 (7.5)	2 (5.6)	2 (11.1)	.101
	Swallow problem	2 (2.9)	3 (4.1)	2 (5.0)	3 (8.3)	0 (0)	.542
	After decannulation	0 (0)	5 (6.8)	0 (0)	0 (0)	3 (16.7)	<.001*
	No ICU SLT involvement	3 (4.3)	3 (4.1)	0 (0)	1 (2.8)	0 (0)	.756
	Refer for communication problems only	3 (4.3)	0 (0)	0 (0)	2 (5.6)	1 (5.6)	.076
	Other	4 (5.7)	4 (5.4)	4 (10.0)	2 (5.6)	0 (0)	.811
Dysphagia assessment^ n=142	BSE	55 (51.4)	27 (62.8)	17 (48.6)	19 (45.2)	4 (44.4)	.912
	FEES	23 (21.5)	6 (14.0)	8 (22.9)	11 (26.2)	3 (33.3)	<.001
	VFS	15 (14.0)	7 (16.3)	7 (20.0)	10 (23.8)	2 (22.2)	.488
	ENT Flexible nasendoscopy	6 (5.6)	2 (4.7)	1 (2.9)	2 (4.8)	0 (0)	.058
	Don't know	7 (6.5)	1 (2.3)	1 (2.9)	0 (0)	0 (0)	.469
	None	1 (0.9)	0 (0)	1 (2.9)	0 (0)	0 (0)	.799
Eat and drink with cuff inflated n=142	Sometimes	31 (64.6)	22 (52.4)	8 (32.0)	13 (68.4)	1 (12.5)	-
	No	4 (8.3)	13 (31.0)	11 (44.0)	4 (21.1)	2 (25.0)	
	Yes	11 (22.9)	5 (11.9)	1 (4.0)	1 (5.3)	0 (0)	
	Don't know	1 (2.1)	0 (0)	3 (12.0)	0 (0)	3 (37.5)	
	Other	1 (2.1)	2 (4.8)	2 (8.0)	1 (5.3)	2 (25.0)	

Question	Response options	Doctor	Nurse	PT	SLT	Dietitian	P value (Fisher's
MOUTHCARE							
Delivery of mouthcare n=142	Yes	6 (12.5)	41 (97.6)	13 (52.0)	12 (63.2)	0 (0)	<.001
	No	42 (87.5)	1 (2.4)	12 (48.0)	7 (36.8)	8 (100.0)	
Responsible for oral hygiene n=142	Nurse	42 (100.0)	1 (100.0)	11 (100.0)	6 (85.7)	7 (87.5)	.097
	Don't know	0 (0)	0 (0)	0 (0)	1 (14.3)	1 (12.5)	
Frequency of oral care n=142	Daily assessment with tool	17 (35.4)	22 (52.4)	6 (24.0)	5 (26.3)	2 (25.0)	.036
	Twice daily mouthcare	21 (43.8)	5 (11.9)	10 (40.0)	9 (47.4)	3 (37.5)	
	Mouthcare on request	0 (0)	1 (2.4)	1 (4.0)	0 (0)	0 (0)	
	Other	10 (20.8)	14 (33.3)	8 (32.0)	5 (26.3)	3 (37.5)	
Oral hygiene advise^ n=142	No advice given	27 (40.3)	5 (4.8)	23 (85.2)	3 (6.1)	6 (75.0)	<.001
	Frequency	10 (14.9)	27 (25.7)	2 (7.4)	12 (24.5)	0 (0)	<.001
	Cleaning products	11 (16.4)	18 (17.1)	1 (3.7)	9 (18.4)	0 (0)	<.001
	Oral hygiene protocol	10 (14.9)	22 (21.0)	0 (0)	5 (10.2)	1 (12.5)	<.001
	Effective technique	3 (4.5)	21 (20.0)	1 (3.7)	11 (22.4)	0 (0)	<.001
	Mouthcare tools	3 (4.5)	12 (11.4)	0 (0)	9 (18.4)	0 (0)	<.001
	Other	3 (4.5)	0 (0)	0 (0)	0 (0)	1 (12.5)	.099

Question	Response options	Doctor	Nurse	PT	SLT	Dietitian	P value (Fisher's
COMMUNICATION							
communication options^ n=141	Low technology aids	42 (87.5)	37 (90.2)	20 (80.0)	16 (84.2)	5 (62.5)	.280
	Advice to patients and family	36 (75.0)	37 (90.2)	23 (92.0)	17 (89.5)	6 (75.0)	.180
	Encourage mouthing	39 (81.3)	33 (80.5)	19 (76.0)	16 (84.2)	3 (37.5)	.117
	High technology aids	16 (3.33)	16 (39.0)	9 (36.0)	14 (73.7)	2 (25.0)	.032
	No special support	2 (4.2)	0 (0)	0 (0)	0 (0)	0 (0)	.679
	Don't know	1 (2.1)	0 (0)	1 (4.0)	2 (10.5)	2 (25.0)	.012
	Other	1 (2.1)	1 (2.4)	1 (4.0)	4 (21.1)	1 (12.5)	.028
Cuff down for speech n=141	Yes	28 (58.3)	15 (35.7)	17 (65.4)	8 (42.1)	1 (12.5)	-
	Sometimes	18 (37.5)	17 (40.5)	5 (19.2)	7 (36.8)	1 (12.5)	
	No	1 (2.1)	9 (22.0)	1 (4.0)	2 (10.5)	0 (0)	
	Don't know	1 (2.1)	0 (0)	2 (7.7)	2 (10.5)	6 (75.0)	
Speaking valves^ n=141	Sometimes	31 (64.6)	23 (57.5)	12 (46.2)	11 (57.9)	3 (37.5)	.528
	No	10 (20.8)	14 (35.0)	4 (15.4)	2 (10.5)	0 (0)	.125
	Always	7 (4.6)	3 (7.5)	8 (30.8)	3 (15.8)	0 (0)	.085
	After nasendoscopy	0 (0)	0 (0)	0 (0)	1 (5.3)	0 (0)	.191
	Other	0 (0)	0 (0)	2 (7.7)	2 (10.5)	5 (62.5)	<.001

Appendix 10Topic guide for semi-structured interviews

Semi-structured interview topic guide

Topics	Questions	***Prompts***
Patient history	Could you tell me about the events leading up to your admission to the ICU? Could you tell me about your stay on the ICU, as you remember it? How long did you stay in ICU? When did you get transferred? Where to?	*How long you were there and what procedures you experienced?* *If poor direct recall, what have you been told?* *If don't know, can I ask your family member about your time in ICU?*
Ventilation and tracheostomy experience	Can you tell me how things progressed with your breathing? Did you need a breathing tube or help to breathe (from a ventilator)? Can you tell me what that felt like? Was there a 'tracheostomy team' that dealt with your trache? Did you understand why you needed it? Do you feel it caused you problems?	*Poor recall – request to ask family member about the situation at the time.* *If tube still in situ, adapt questions to discuss difference with ongoing care.* *Give time for patient to reflect on their experience and recall examples, which add richness to data.*
Communication ability	Did you have difficulty being able to communicate whist in ICU? Can you tell me how this made you feel? How did you resolve these problems? Were you offered any communication aids? Were you seen by a Speech and Language Therapist?	*Valuable to explore whether patient found their own solutions or needed guidance.* *Probe whether the physical restrictions were an added challenge that made access to communication charts difficult?*
Feeding – oral intake vs. nasogastric/PEG	Was there any time that you were told you weren't allowed to eat or drink? Did you need to be fed through a tube? Was that in your nose or into your stomach? Was the process explained to you? Were you seen by any specialists or therapists to investigate your swallowing? How did you feel about that process and the decisions made?	*Involvement in decision-making?* *Important to reflect on personal impact on the restriction of oral intake*
Mouthcare	Did you have your teeth cleaned regularly, when you wanted whilst you were in ICU? Did you have any problems with either too much or too little saliva in ICU? How was that managed?	*Are they able to brush their own teeth? Are they satisfied with the way another person cleans?* *Any preferred tools?*
Things to Improve?	Tell me is there anything that you feel could have been improved in your care? Do you have any questions for me?	*Participants are free to reflect on their hospital admission and generate an idea from their own perspective that they consider would have a more positive impact.*

Appendix 11 Sample coding for thematic analysis of theme of ‘Communication’

Theme: Communication

Sample coding for: Breakdown of communication
INT002 Reference 1 So, when you have the cuff down for short periods of time, do you enjoy that opportunity to use your voice? R1: "Very uncomfortable." I: So, you enjoy it a bit, but it’s also very uncomfortable? Okay. Tell me about the discomfort. Where do you feel that? “Makes your breathing heavy’, Okay R1: "And ….more secretions."
Reference 2 "So, 15–30 minutes cuff down session…..the visitors cannot lip read."
Reference 3 Do you find people treat you differently because they can’t hear your voice? R1: “Yes” I: And I presume it’s not in a positive way? [Laughter] R1: "No"
INT08 Reference 3 I remember not being able to talk. And it was frustrating because I tried to talk, but nothing would come out. C: So we were trying to sort of lip-read, weren’t we? Charades and the whole blinking lot. But it was very, very difficult to understand what it was he was trying to say.
Sample coding for: Alternatives to talking
INT05 Reference 1 Did you have any communication aids ever? Did anyone get you any charts or things to spell out words? C: Yes, we did, didn’t we? And someone brought a computer keyboard thing that they thought you would be… But because R couldn’t use his hands, we didn’t get anywhere very much with that, did we? R: With the charts, people tried to anticipate what you wanted to say, which just created more confusion. C: Yes. R: But we survived, we are here now and we’ve got a voice.

Appendix 11 Sample coding for thematic analysis of theme of ‘Communication’

INT03 Reference 1

Your dad did that?

C: Yes, just a simple letter board with the alphabet.

I: Did the hospital not provide you with anything? Because that was going to be my next question. Did they set you up with something to communicate?

C: No. My dad made us just a piece of cardboard with the letters on and I’d write it down for him.

I: Did you find that helped?

R: Quite a lot.

I: Yes? Was it hard to use that, took time?

R: To start with, yes, but then it became more natural.

I: Yes.

R: But it really helped, yes.

Sample coding for: effective communication

INT07 Reference 1

We were given the E-tran board. Fairly early on you were taught with whoever it was how to use it, and then she taught that to us, how to use it.

I: Do you remember trying to use that? Eye-pointing?

R: Yes.

I: Was it successful?

R: Yes.

Reference 2

By then we’d managed to... because we did spend some time trying to lip-read what you were saying, which was hard work, and just still is anyway. Because the E-tran board couldn’t come up, I was quite distressed at this thought that we wouldn’t be able to have any communication again. So we rang S2 and I think within 24 hours they got another E-tran board up, which was really good.

I: So that was quite a reliable and useful communication tool?

C: Yes. That worked very well. Very short answers, and if we did go with anything longer we started learning we’ve got to write it down.

INT08

She’s helping me with trying to talk without forcing it out. So she’s trying to help me talk with a lower level of volume rather than forcing it out. People can’t really understand. And just talk like this. We’ve worked on…articulation, as well. And then it all comes back to this, my larynx.

Appendix 12 Additional themed excerpts from participant interviews

Adjustment	*I remember being put in the ambulance, but that's all I remember…The main thing that did upset me was…when they said, "We can operate…You've got one chance out of ten of survival. Or stay like you are." I said, "No, I'll go for it." I didn't tell [wife]. When they took me out, I didn't think I would be coming back. (Arthur)* *They did tell us a little bit of what was happening and we just had a consultation with the consultant that did the surgery, didn't give us a lot of hope at that time, didn't know whether he was going to survive, even, you know. So we've just so much to be thankful for. We didn't expect a recovery even this far. So yes, so he's done well. (George's wife)* *There are letters that we've had that said there would be a 2%-3% chance of complete tetraplegia from the surgery, but he [the surgeon] said that he wasn't anticipating that. He didn't see that that would be an issue at all…worst case scenario was death or tetraplegia…The surgeon was always adamant that Simon would be okay. He said he didn't know why Simon wasn't rallying, other than the sepsis had caused damage to an already weakened state…because Simon was ill with pneumonia and sepsis…I think whilst they were sorting all of that stuff out, the prognosis…was kind of probably not even looked at. The first prognosis we had…was done in [Hospital 2]. (Simon's wife)* *No, that [mouthcare] never really bothered me too much. And I'm still having my teeth cleaned for me, and that's not so bad. It's more to do with things like bowel care…and that sort of thing, which I do feel I…find a bit difficult. I'm always going to have to have that, so I've somehow got to get used to it, but it's only recently that I've actually tried to come to terms with it and I'm not finding it very easy.(Margaret)* *I'm nearly absolutely sure we are going home to our original house, but we did think about moving because it's an old house…but there were just two areas where they had to make certain that they could get round the corner with a wheelchair…So I think that is what it will be. But I can foresee a few hiccups. I just have to hope it'll be okay, but that's what everyone leaving here must think. Everyone's different but they've all got to rearrange their lives. And I don't want to go anywhere else because we've got such good friends around, and I think that is so important. (Margaret)* *That's my aim, is to get him to Blackpool, because we used to go every year. (Arthur's wife)* *Because [girlfriend] lives in [town], so it's a long way from here and, obviously, when Ryan's accident happened she didn't go back to work, because she still lived in [town] and we were having to go down to London every day to see Ryan, training it or driving. We did get the use of a house while we were down there as well, which was quite good for the odd overnight stay. She essentially moved in with us for five weeks, didn't go home very much at all because we were just going backwards and forwards to the hospital. (Ryan's mum)* *Oh, I'm so overwhelmed. I think the entire village has been down [to visit]. (Keith)* *They've been quite good. They've come and offered help and stuff like that, because we've got this bungalow that, touch wood, should be ours…they've got to write reports…and the next thing…we are going to get the care plan and everything. One of them are going to*

	come along. I understand everything, but sometimes…I can go away afterwards and think…why didn't I say that, whereas because they've been through it…So I have asked them if they'll come along to the care plan meeting, and they've said, yes that's no problem, just let them know when it is. (Arthur's wife)
Transitions	*I remember after about two weeks, when I was...sounding a bit more coherent, I remember saying, "This is wonderful, I had no idea hospitals were like this." Amazing. After having said the whole thing was dreadful...(Margaret)* *For me, I thought it was [Hospital 2]'s prerogative to bide your time till they could get you here [to a spinal unit]…The spinal side, they had no idea. (George)* *There was no procedure to get to a specialist spinal unit…they didn't have a ventilated bed…The goalposts changed, with the spinal units being divided in deciding the various criteria to do with breathing and capacity. (Roger)* *But then…that Dr…thought he should have gone to…[a specific spinal unit] but we were never given that option, we were never told about that… all we knew is we were going to [a different spinal unit] and then we were told he definitely wasn't going to [any spinal unit]. (Arthur's wife)* *At some point they'd made a decision to refer him. She came up in October and put him on the bed list for [a spinal unit], but because of the ventilation needs obviously he was fighting for minority of beds, so [Hospital 1] said that what they were doing for him in [Hospital 1] was nothing that couldn't be done in [Hospital 2]…and that he would be better off up in [Hospital 2] where family were nearby rather than in [Hospital 1]…We weren't involved in the [Hospital 2] decision, actually…we were just told that that was the preferred route. I said I wanted him to be where the best care was, and if that was in [Hospital 1] that was fine. That wasn't an issue. He needed to be where he was going to get the best level of care. (Simon's wife)* *So when they then brought up [Hospital 2], I was, like we'll go for [Hospital 2]. It's a lot nearer if you're going to call me on a Sunday [for an emergency].' He was going straight into intensive care anyway, so that was a relief then. (Simon's wife)* *We knew it was on the card for weeks before we actually went. (Keith's wife)* *[Hospital 3] was a really good hospital, I think they really tried, because compared to [Hospital 2]…when I went to [Hospital 2] I thought it was really good, then I got to [Hospital 3]. (Paula) Coming to [spinal unit], George was not prepared for it. You were never explained about your spinal injury…you weren't prepared for the shock of actually seeing patients in wheelchairs or told that there is a possibility you might need a wheelchair either permanently or temporary, whatever the outcome would be. (George's wife)* *I mean, the spinal side, they had no idea…it was a poor handover between [Hospital 1] and [Hospital 2]. They tried to change your ventilation as soon as you got there. I had a feeling that… the nurse who actually took the handover didn't really…listen, because the first thing, when I went in, he was up quite high in bed…and I said,*

	"Excuse me, can I ask what angle he's at?" So she told me "we keep all our ventilated patients…" I said, "Sorry, but George is not a ventilated patient, George is a spinal patient." So she then was flicking through all the pages, and the bed went down. (George's wife) *They said that [the spinal unit]…were very, very short of ventilator beds…They were starting [ventilator weaning] at [Hospital 2] before we left, but they were pushing him very quickly, and instead of taking it steadily…they said, "Oh we'll just let him go for an hour the next time and just push it fairly rapidly." He got another chest infection, which he was transferred over [with]. The last two days before he came…they were suctioning him every half hour and nobody was paying any attention to it, basically. (George's wife)* *I could not go home because the modifications to the house that are required, they're underway. (Roger)* *We are not very far along, except I've measured the doors and decided that they'll probably need widening if you are still in your wheelchair. (Keith's wife)* *Well we need to look at finance and funding at some stage, but that's as far as it's gone. And the OTs have requested that we look at the house and see what needs to be put in place, because we haven't got a downstairs bathroom…But we have got a nice straight, not too tall, not too steep stairs, so it would take a stairlift quite nicely. (George)*
"The golden opportunity"	*As far as I understood, they [staff at rehabilitation unit] were in charge of all of the transport that had been all sorted, and Simon would go on the Monday morning, which was really good. Then I don't know what happened with transport on the Monday morning, but there was an issue…because that never materialised...then [Outreach nurse at spinal unit] said, 'We can only keep the bed until Tuesday morning. If we can't guarantee to get him up here, sorry we can't keep the bed.' I was having kittens, absolute kittens. I think upset might be a minor level. Me and your parents were absolutely fuming…you just wanted to shout at anybody who was not doing something to make this happen, because there was a golden opportunity, absolute golden opportunity, and it appeared to be slipping away out of our hands. Again, it all comes down to the desire for Simon to be able to speak. (Simon's wife)* *The difference that we didn't quite grasp when we first came here was that he needed to organise himself, and if you are not told that - and we weren't really told that - I think you missed a few sessions to start with because you were sort of waiting for somebody to come and get you. He can't get himself into his chair and he also can't get himself to places…(Ryan's mother)* *He could move more when he was in the ITU in [Hospital 2]. Within a week of going in the spinal unit, he couldn't move anything…I mean my daughter for a month went home from the spinal unit in tears, because she says she'd get there and Roger would be just sitting looking at four walls. It's not the wonderful experience everybody makes it out to be. (Roger's wife)* *I don't think [the doctor] [at spinal unit] necessarily thought you were a candidate that would benefit from coming to be quite honest.*

	(Keith's wife) *Because he said to me…"When was your accident?" so I said, "September" He said "Where did you go?" I said, "Hospital 1." He said, "Well, Hospital 1 should have sent you straight here [to spinal unit]. "You should have been and gone by now." (Keith)*
"When you can't eat"	*…they explained that they couldn't be certain that it wouldn't go down the wrong way and go into my lungs and they couldn't take that chance, which I suppose…whether that was the whole reason or not, but I suppose it could be, it makes sense. I did argue with them occasionally and said look, I've never had any problems…my throat seems fine...but anyway, they just kept reiterating that I'd had an infection, and this was the way they had to go. (Margaret)* *…that I was incapable of eating (George)* *Probably about two weeks into [Hospital 2] you had a swallow test. They tried you with some sips of fluid and you just aspirated, so they stopped it…I think they did it twice and he aspirated both times. (George's wife)* *Because I wasn't even allowed to have water, I had these sponges, you know, I was only allowed to wet my lips, and that was driving me mad because I've always drunk a lot of water, and that's all I wanted, a glass of water for a while. (Margaret)* *He'd had a small bit of input of speech and language in [Hospital 1]. Before the tracheostomy was done, there was probably a very small window of time where they did a swallow test…and that went fine. Then [he] became very ill and then obviously couldn't do any swallow tests. They did do another swallow test with the blue dye after the trache, but [he'd] aspirated that. So that was just left…that he wasn't swallowing and eating. (Simon's wife)* *"I couldn't swallow…Part of the swallow went into my lungs. It was fine most of the time at [Hospital 1]. In my mind, [swallow problem] is linked to the tracheostomy". (Roger)* *I had one where they put a camera on a tube down my throat just to test my swallow and to see if I still needed a thickener…I still needed thickener, but I could eat. And then later on in the rehab ward I had a side-on x-ray as I swallowed…that one was much better. From then on I could get rid of the thickener and drink normally. (Ryan)* *…they had a SALT team, speech and language, [at hospital 2] but I could only see them once a week and I was so desperate to eat and drink. (Paula)* *We've had about a week, two weeks of fruit puree. And today was the first day she took me through a pureed meal, a hot meal. (George)* *The first time he had an orange squash he was like, "Oh my God, that is wonderful." He was so happy. Then they started you with a bit of soup…Yes, slowly. I mean, it did happen slowly. I mean, we did get to a point where he was on proper meals. (Arthur's wife)*
Communication	*It was difficult before because I couldn't make a sound at all. So I had to mouth for ages. Some people can understand better than*

	others but before it was a nightmare. (Paula) *It would be that I…[was] getting frustrated, the fact you couldn't get across what you wanted to get across, you tried and…Get frustrated and lose my patience. Shout. (George)* *We were trying to sort of lip-read, weren't we? Charades and the whole blinking lot. But it was very, very difficult to understand what it was he was trying to say. We'd just sort of say, "Don't worry about it Ryan. Don't get upset about it. Don't use up your energy." (Ryan's mum)* *You got cross and say, "Forget it." wouldn't you? You'd mouth "forget it." (Keith's wife)* *And at [Hospital 2], bless them, if they didn't understand, they'd find somebody and they'd come along and say, "Say it slowly" You know, it's a long process. (Keith)* *He's having that cuff down in therapy, where they deflate the cuff a little bit, and then we can hear his voice. But we have to mind his oxygen levels though, so the physio is doing that in here. (Roger's wife)* *Just a simple letter board with the alphabet. My dad made us just a piece of cardboard with the letters on and I'd write it down for him. (Arthur's wife)* *Quite a lot. To start with [it was hard], yes, but then it became more natural…it really helped, yes. (Arthur)* *With the charts, people tried to anticipate what you wanted to say, which just created more confusion. (Keith)* *No, because of my voice, but my parents could. (Simon)* *One of the things that was concerning was the E-tran board wasn't allowed to travel with us because it belonged to [Hospital 1]. By then we…did spend some time trying to lip-read what you were saying, which was hard work, and just still is anyway. Because the E-tran board couldn't come up, I was quite distressed at this thought that we wouldn't be able to have any communication again. So we rang [Hospital 2] and I think within 24 hours they got another E-tran board up, which was really good. (Simon's wife)* *We had a lot of use out of that. That was really good. [Young son] knew how to work it. He'd hold it and go, 'What letter, daddy? What letter?' Do you remember him doing that? He held it right over his face. 'What letter, daddy? What letter? What letter, daddy?' He just pressed random buttons. It didn't matter what Simon was saying. 'Blue, did you want blue?' And Simon would just go, 'Yes' 'Did you want black?' 'Yes.' You were talking to him, and [Young son] loved it, because he was talking to you. (Simon's wife)* *We then moved on to the TOBI computer for the special effect, and you were brilliant at the computer but you did get tired with using just the eyes, and stuff. (Simon's wife)* *…they had them with vowels down the side and then across and I used to just point to the letters until we… sometimes we had to write them down…Most of the time it was fine, wasn't it? There were odd times when it was frustrating…it certainly made a difference for me.*

Appendix 12 Additional themed excerpts from participant interviews

	(George's wife) *[it was] alright when you got the right letter…Staff didn't use it…If they did it was only once or twice. (George)*
"In the hands of the nurses and doctors"	"This is it….and you'll have to accept it" *It was four months after the operation, and they were saying, "He won't eat. He won't talk. He won't breathe independently"…I guess that sort of prognosis...I wasn't accepting that Simon wouldn't speak. It was just too much hard work. I wasn't going to sit there and accept it without having tried all manner of stuff. People just don't seem to be willing to try to find out why that [tracheostomy] cuff won't go down. (Simon's wife)* Staff contact *The staff on the intensive care were very good at explaining things…but the two doctors, in fact, the ones that were always helping him, were absolutely brilliant. (Roger's wife)* *The nurses didn't ever look after the same patient for more than one day, and also I particularly felt…they were so interested in the machines – the respirator, the drips, all the things, they would be checking them, and quite often never say to Keith, "How are you today?" or, "Is there anything we can get you?"…So he was ignored completely as almost being a bit of the machinery. (Keith's wife)* *The speech and language...from my point of view we didn't really see a lot of her with regards to swallow…I think it was just left that he wasn't swallowing and eating. (Simon's wife)* Personal Kindness *We ended up with him taking chocolate buttons…The doctor did your food…A bit of a take-a-risk doctor. You know, risk-assessed risk, as it were, which we were pleased with. They were good moves and it meant that Simon's quality of life was picking up, if only slightly. (Simon's wife)*

	TOPIC	ORIGINAL STATEMENT	STEERING GROUP DECISION	REVISED STATEMENT	COMMENTS SUBMITTED
1.	pre-morbid	If a CSCI patients is under 60 years, they are likely to have swallowing problems	KEEP	If a CSCI patients is over 60 years, they are likely to have swallowing problems	
2.	pre-morbid	If a CSCI patients is over 60 years, they are likely to have swallowing problems	DISCARD		
3.	pre-morbid	If a CSCI patients is male, they are likely to have swallowing problems	DISCARD		
4.	pre-morbid	If a CSCI patients is female, they are likely to have swallowing problems	DISCARD		
5.	co-morbid	If a CSCI patient has a brain injury, they are likely to have swallowing problems	REPHRASE	If a CSCI patient has a brain injury, they are more likely to have swallowing problems	depends on where and how significant
6.	co-morbid	If a CSCI patient has tetraplegia (paralysis of all four limbs) they are likely to have swallowing problems	KEEP	If a CSCI patient has tetraplegia (paralysis of all four limbs) they are likely to have swallowing problems	depends on how high and how incomplete
7.	co-morbid	If a CSCI patient has a cognitive impairment, they are likely to have swallowing problems	REPHRASE	If a CSCI patient has a cognitive impairment, they are more likely to have swallowing problems	more likely
8.	co-morbid	If a CSCI patient has an injury between C1 to C4, they will require a swallowing assessment	KEEP	If a CSCI patient has an injury between C1 to C4, they will require a swallowing assessment	
9.	co-morbid	If a CSCI patient has an injury between C5 to C7, they will require a swallowing assessment	KEEP	If a CSCI patient has an injury between C5 to C7, they will require a swallowing assessment	
10.	co-morbid	If a CSCI patient has a thoracic level injury, they will require a swallowing assessment	KEEP	If a CSCI patient has a thoracic level injury, they will require a swallowing assessment	
11.	co-morbid	If a CSCI patient has a complete ASIA A injury, they will require a swallowing assessment	REPHRASE	If a CSCI patient has a complete spinal cord injury (AIS A) they will require a swallowing assessment	Using complete and ASIA A might cause confusion.
12.	co-morbid	If a CSCI patient has an incomplete injury, ASIA levels B to D, they will require a swallowing assessment	KEEP	If a CSCI patient has an incomplete spinal cord injury (AIS level B to D) they will require a swallowing assessment	
13.	co-morbid	If a CSCI patient has anterior cervical spine surgery, they are likely to have swallowing problems	KEEP	If a CSCI patient has anterior cervical spine surgery, they are likely to have swallowing problems	
14.	co-morbid	If a CSCI patient has posterior spinal surgery, they are likely to have swallowing problems	REPHRASE	If a CSCI patient has posterior cervical spinal surgery, they are likely to have swallowing problems	posterior cervical spinal surgery
15.	co-morbid	If a CSCI patient has a respiratory impairment, they are likely to have swallowing problems	KEEP	If a CSCI patient has a respiratory impairment, they are likely to have swallowing problems	
16.	definition	Dysphagia in CSCI is characterised by facial	KEEP	Dysphagia in CSCI is characterised by facial	

		weakness		weakness	
17.	definition	Dysphagia in CSCI is characterised by lip weakness	KEEP	Dysphagia in CSCI is characterised by lip weakness	
18.	definition	Dysphagia in CSCI is characterised by tongue weakness	KEEP	Dysphagia in CSCI is characterised by tongue weakness	
19.	definition	Dysphagia in CSCI is characterised by velopharyngeal (soft palate) weakness	KEEP	Dysphagia in CSCI is characterised by velopharyngeal (soft palate) weakness	
20.	definition	Dysphagia in CSCI is characterised by a weak voice	KEEP	Dysphagia in CSCI is characterised by a weak voice	
21.	definition	Dysphagia in CSCI is characterised by a wet sounding voice.	KEEP	Dysphagia in CSCI is characterised by a wet sounding voice.	
22.	definition	Dysphagia in CSCI is characterised by coughing after drinking or eating.	KEEP	Dysphagia in CSCI is characterised by coughing after drinking or eating.	
23.	definition	Dysphagia in CSCI is characterised by food or fluid coming out of the tracheostomy tube after eating.	KEEP	Dysphagia in CSCI is characterised by food or fluid coming out of the tracheostomy tube after eating.	
24.	definition	Dysphagia in CSCI is characterised by food or fluid being aspirated into the lungs.	KEEP	Dysphagia in CSCI is characterised by food or fluid being aspirated into the lungs.	Dysphagia in CSCI can be characterised by…
25.	definition	Dysphagia in CSCI is characterised by difficulty of food or fluid passing from the mouth to the oesophagus.	KEEP	Dysphagia in CSCI is characterised by difficulty of food or fluid passing from the mouth to the oesophagus.	
26.	definition	Dysphagia in CSCI is characterised by delayed swallow initiation.	REPHRASE	Dysphagia in CSCI can be characterised by delayed swallow initiation.	Will assessors be able to define delayed swallow initiation.
27.	definition	Dysphagia in CSCI is characterised by reduced laryngeal elevation.	REPHRASE	Dysphagia in CSCI can be characterised by reduced laryngeal elevation.	Will assessors be able to define reduced laryngeal elevation.
28.	definition	Dysphagia in CSCI is characterised by impaired laryngeal sensation.	REPHRASE	Dysphagia in CSCI can be characterised by impaired laryngeal sensation.	Dysphasia in CSCI can be characterised by impaired laryngeal sensation

29.	definition	Dysphagia in CSCI is characterised by a weak cough.	REPHRASE	Aspiration risk secondary to dysphagia in CSCI is increased without protection of an effective cough	Aspiration risk secondary to dysphasia following CSCI is increased without protection of effective cough
30.	definition	Dysphagia in CSCI is characterised by an absent cough reflex.	REPHRASE	Dysphagia in CSCI can be characterised by an absent cough reflex.	
31.	screening	If a CSCI patient has a prolonged intubation, this will affect normal laryngeal function	REPHRASE	If a CSCI patient has a prolonged intubation (>48 hours) this will affect normal laryngeal function	state what constitutes prolonged intubation ? >48 hours
32.	screening	If a CSCI patient has a tracheostomy in situ, this will affect normal laryngeal function	KEEP	If a CSCI patient has a tracheostomy in situ, this will affect normal laryngeal function	
33.	screening	If a CSCI patient needs invasive ventilation, this will affect normal laryngeal function	KEEP	If a CSCI patient needs invasive ventilation, this will affect normal laryngeal function	
34.	screening	If a CSCI patient needs non-invasive ventilation this will affect laryngeal function.	KEEP	If a CSCI patient needs non-invasive ventilation this will affect laryngeal function.	
35.	screening	If a CSCI patient has the cuff inflated on the tracheostomy tube, this will affect normal laryngeal function	KEEP	If a CSCI patient has the cuff inflated on the tracheostomy tube, this will affect normal laryngeal function	
36.	screening	If a CSCI patient has to remain lying in supine, this will make swallowing unsafe	REPHRASE	Having to lie in supine for prolonged periods can make swallowing unsafe	
37.	screening	Dysphagia in CSCI is assessed by looking at oral-motor function on command.	KEEP	Dysphagia in CSCI is assessed by looking at oral-motor function on command.	
38.	screening	Dysphagia in CSCI is assessed by looking at laryngeal elevation when eating and drinking.	KEEP	Dysphagia in CSCI is assessed by looking at laryngeal elevation when eating and drinking.	Will non specialists be able to answer this?
39.	screening	Dysphagia in CSCI is assessed by looking at laryngeal sensation when eating and drinking.	KEEP	Dysphagia in CSCI is assessed by looking at laryngeal sensation when eating and drinking.	Will non specialists be able to answer this?
40.	screening	Dysphagia in CSCI is assessed by the loudness of the voice produced.	KEEP	Dysphagia in CSCI is assessed by the loudness of the voice produced.	

41.	screening	Dysphagia in CSCI is assessed by looking at how effectively oral secretions are managed.	REPHRASE	Dysphagia in CSCI is assessed by looking at how effectively oral secretions are managed by the patient.	how effectively the patient is able to manage oral secretions vs nurse etc as this could include yankeur
42.	screening	Dysphagia in CSCI is assessed by giving a swallowing trial of water to see if the patient coughs.	KEEP	Dysphagia in CSCI is assessed by giving a swallowing trial of water to see if the patient coughs.	
43.	screening	Dysphagia in CSCI is assessed by giving a swallowing trial of yoghurt to see if the patient coughs.	KEEP	Dysphagia in CSCI is assessed by giving a swallowing trial of yoghurt to see if the patient coughs.	
44.	screening	Dysphagia in CSCI is assessed by using blue dye in food or fluids to see if the patient aspirates.	KEEP	Dysphagia in CSCI is assessed by using blue dye in food or fluids to see if the patient aspirates.	
45.	screening	If a CSCI patient has poor respiratory function, this will make swallowing unsafe.	REPHRASE	If a CSCI patient has deteriorating respiratory function, this can make swallowing unsafe.	
46.	screening	If a CSCI patient has a forced vital capacity (FVC) below one litre, this will make swallowing unsafe.	REPHRASE	If a CSCI patient has a forced vital capacity (FVC) below one litre, this can make swallowing unsafe.	
47.	screening	If a CSCI patient has a reduced Forced Expiratory Volume in 1 second (FEV1) this will make swallowing unsafe.	REPHRASE	If a CSCI patient has a reduced Forced Expiratory Volume in 1 second (FEV1) this can make swallowing unsafe.	
48.	assessment	Dysphagia in CSCI is best assessed by using videofluoroscopy	REPHRASE	Videofluoroscopy is the best instrumental assessment to diagnose dysphagia in CSCI	
49.	assessment	Dysphagia in CSCI is best assessed by using flexible nasendoscopy.	REPHRASE	Flexible nasendoscopy is the best instrumental assessment to diagnose dysphagia in CSCI.	
50.	assessment	Dysphagia in CSCI is best assessed by a clinical bedside evaluation.	REPHRASE	Clinical bedside evaluation is the best instrumental assessment to diagnose dysphagia in CSCI.	
51.	assessment	Dysphagia in CSCI can only be assessed when the patient can be sat upright	REPHRASE	Dysphagia in CSCI is best assessed when the patient can be sat upright.	
52.	assessment	Allowing a CSCI patient to aspirate is the only way to demonstrate the presence of dysphagia	REPHRASE	Evidence the patient has aspirated is the only way to demonstrate dysphagia in CSCI	Evidence the patient has aspirated is the only way to demonstrate dysphagia in CSCI (most people will not willingly allowing aspiration to occur)

53.	identification	Evidence of dysphagia is increased frequency of tracheal suction.	REPHRASE	Evidence of dysphagia is suctioning food and/or fluids via tracheal suction	?Evidence of dysphagia is suctioning food and/or fluids via tracheal suction
54.	identification	Evidence of dysphagia is a spiking pyrexia	REPHRASE	Spiking pyrexia can be evidence of dysphagia	
55.	identification	Evidence of dysphagia is a chest infection.	REPHRASE	A chest infection can be evidence of dysphagia.	
56.	identification	Evidence of dysphagia is dropping oxygen saturations.	DISCARD		
57.	identification	Evidence of dysphagia is increased frequency of oral suction.	REPHRASE	Increased frequency of oral suction via yankeur can be evidence of dysphagia.	
58.	identification	A serum albumin value of <3.5g/dl demonstrates nutritional problems relating to dysphagia	REPHRASE	A serum albumin value of <3.5g/dl can suggest nutritional problems relating to dysphagia	Are labs reference ranges all the same for serum albumin?
59.	identification	A serum pre-albumin level of < 15 mg/ml demonstrates nutritional problems relating to dysphagia	REPHRASE	A serum pre-albumin level of < 15 mg/ml can suggest nutritional problems relating to dysphagia	Are labs reference ranges all the same for serum albumin?
60.	management	Patients with a cervical SCI should be allowed to eat until there is evidence of a swallowing problem.	KEEP	Patients with a CSCI should be allowed to eat until there is evidence of a swallowing problem.	sorry no idea
61.	management	Patients with a cervical SCI should be kept nil by mouth until assessed for evidence of a swallowing problem	KEEP	Patients with a CSCI should be kept nil by mouth until assessed for evidence of a swallowing problem	sorry, no idea
62.	management	Patients with a cervical SCI should be allowed to drink thin fluids unless there is evidence of a swallowing problem.	KEEP	Patients with a CSCI should be allowed to drink thin fluids unless there is evidence of a swallowing problem.	
63.	management	Patients with a cervical SCI should drink thickened fluids if there is evidence of a swallowing problem	KEEP	Patients with a CSCI should drink thickened fluids if there is evidence of a swallowing problem	
64.	management	Patients with a cervical SCI should be stopped from eating only if they cough.	REPHRASE	Patients with a CSCI should be stopped from eating and drinking if they demonstrate consistent coughing.	
65.	management	Patients with a cervical SCI should be fed via NG tube if there is evidence of a swallowing problem	REPHRASE	Patients with a CSCI should be fed via NG tube initially if swallow is unsafe and nutrition is to be maintained.	initially if swallow is unsafe and need to maintain nutrition

66.	management	Patients with a cervical SCI should have a gastrostomy tube if there is evidence of a swallowing problem	REPHRASE	Patients with a CSCI should have a gastrostomy tube if problems persist for more than 4-6 weeks	if unable to meet their nutritional needs in the long term
67.	management	Patients with a cervical SCI should have tracheostomy cuff **deflated** when taking oral intake to reduce risk of aspiration	KEEP	Patients with a CSCI should have tracheostomy cuff deflated when taking oral intake to reduce risk of aspiration	
68.	management	Patients with a cervical SCI should have the tracheostomy cuff **inflated** when taking oral intake to reduce risk of aspiration	DISCARD		
69.	management	Patients with a cervical SCI requiring 24 hour ventilation should not eat to reduce risk of aspiration	KEEP	Patients with a CSCI requiring 24 hour ventilation should not eat to reduce risk of aspiration	not true but need therapy to retrain and achieve safe swallow
70.	management	Patients with a cervical SCI should only eat when they are off ventilation to reduce risk of aspiration	KEEP	Patients with a CSCI should only eat when they are off ventilation to reduce risk of aspiration	
71.	management	Patients with a cervical SCI and dysphagia cannot be safely weaned off ventilation.	REPHRASE	Patients with a CSCI and dysphagia cannot be safely weaned off mechanical ventilation.	mechanical ventilation
72.	management	Patients with a cervical SCI and dysphagia should not use speaking valves.	REPHRASE	Patients with a CSCI and dysphagia should not use in-line speaking valves.	? separate out to include inline speaking valve
73.	management	Patients with a cervical SCI should be allowed to eat when lying in a supine position.	KEEP	Patients with a CSCI should be allowed to eat when lying in a supine position.	if have had FEES and safe swallow determined
74.	management	Patients with a cervical SCI should be allowed to eat in a semi-recumbent/30 degree position.	KEEP	Patients with a CSCI should be allowed to eat in a semi-recumbent/30 degree position.	if have had FEES and safe swallow determined
75.	management	Patients with a cervical SCI should only be allowed to eat when they are in an upright position.	KEEP	Patients with a CSCI should only be allowed to eat when they are in an upright position.	ideally in an upright position but can eat and drink in other positions
76.	management	Patients with a cervical SCI are at high risk of ventilator associated pneumonia due to their supine position.	KEEP	Patients with a CSCI are at high risk of ventilator associated pneumonia due to their supine position.	but WOB is usually easier|Keep Question
77.	management	Patients with a cervical SCI require regular oral hygiene to reduce the risk of ventilator associated pneumonia.	KEEP	Patients with a CSCI require regular oral hygiene to reduce the risk of ventilator associated pneumonia.	

78.	management	Patients with a cervical SCI experience a dry mouth due to the effects of medication.	KEEP	Patients with a CSCI experience a dry mouth due to the effects of medication.	
79.	management	Patients with a cervical SCI require regular moisturising of the oral mucosa to alleviate a dry mouth.	KEEP	Patients with a CSCI require regular moisturising of the oral mucosa to alleviate a dry mouth.	
80.	management	Patients with a cervical SCI need regular sips of water to relieve a dry mouth.	KEEP	Patients with a CSCI need regular sips of water to relieve a dry mouth.	if able to manage their oral secretions
81.	management	Patients with acute CSCI can use alternative communication aids to communicate effectively.	REPHRASE	Acute CSCI patients should use alternative communication aids to communicate effectively.	should use vs. can use
82.	management	Patients with CSCI communicate most effectively through being able to use their voice.	REPHRASE	Acute CSCI patients should use their own voice to communicate effectively.	
83.	management	If a CSCI patient has a paralytic ileus they should be kept nil by mouth until it resolves.	KEEP	If a CSCI patient has a paralytic ileus they should be kept nil by mouth until it resolves.	
84.	therapeutic intervention	The goal of therapy is for the CSCI patient to return to safe eating and drinking.	KEEP	The goal of therapy is for the CSCI patient to return to safe eating and drinking.	
85.	therapeutic intervention	The goal of therapy is to help the patient with CSCI to communicate through talking.	KEEP	The goal of therapy is to help the patient with CSCI to communicate through talking.	
86.	therapeutic intervention	CSCI patients with dysphagia benefit from daily swallow therapy to improve swallow safety	KEEP	CSCI patients with dysphagia benefit from daily swallow therapy to improve swallow safety	
87.	therapeutic intervention	The goal of therapy is to prevent aspiration through keeping tracheostomy cuff inflated.	REPHRASE	The goal of swallow therapy is to prevent aspiration by keeping tracheostomy cuff inflated whilst eating.	
88.	therapeutic intervention	The goal of therapy intervention is to prevent aspiration by keeping the CSCI patient nil by mouth and fed via NGT/PEG.	REPHRASE	The goal of swallow therapy is to prevent aspiration by keeping the CSCI patient nil by mouth and fed enterally via tube.	
89.	therapeutic intervention	The goal of therapy is for the CSCI patient to be able to self-ventilate without a tracheostomy.	REPHRASE	The goal of team intervention is for the CSCI patient to be able to self-ventilate without a tracheostomy.	
90.	therapeutic intervention	Dysphagia in CSCI is a permanent state and is not expected to improve.	REPHRASE	Dysphagia in CSCI is a permanent state and is unlikely to improve.	

State-ment no.	Supercategory	category	sub category	round 1
1	co-morbid status	age	over 60 yrs	If a CSCI patients is over 60 years, they are likely to have swallowing problems
2	co-morbid status	co-morbidities	neurological	If a CSCI patient has a brain injury, they are more likely to have swallowing problems
3	co-morbid status	co-morbidities	physical	If a CSCI patient has tetraplegia (paralysis of all four limbs) they are likely to have swallowing problems
4	co-morbid status	co-morbidities	cognitive	If a CSCI patient has a cognitive impairment, they are more likely to have swallowing problems
5	co-morbid status	spinal cord level	C1 to C4	If a CSCI patient has an injury between C1 to C4, they will require a swallowing assessment
6	co-morbid status	spinal cord level	C5 to C7	If a CSCI patient has an injury between C5 to C7, they will require a swallowing assessment
7	co-morbid status	spinal cord level	thoracic	If a CSCI patient has a thoracic level injury, they will require a swallowing assessment
8	co-morbid status	spinal cord severity	complete ASIA A	If a CSCI patient has a complete spinal cord injury (AIS A) they will require a swallowing assessment
9	co-morbid status	spinal cord severity	Incomplete ASIA B-D	If a CSCI patient has an incomplete spinal cord injury (AIS level B to D) they will require a swallowing assessment
10	co-morbid status	spinal surgery	anterior spinal surgery	If a CSCI patient has anterior cervical spine surgery, they are likely to have swallowing problems
11	co-morbid status	spinal surgery	posterior spinal surgery	If a CSCI patient has posterior cervical spinal surgery, they are likely to have swallowing problems
12	co-morbid status	respiratory	respiratory	If a CSCI patient has a respiratory impairment, they are likely to have swallowing problems
13	definition	dysphagia	oromotor function	Dysphagia in CSCI is characterised by facial weakness
14	definition	dysphagia	oromotor function	Dysphagia in CSCI is characterised by lip weakness
15	definition	dysphagia	oromotor function	Dysphagia in CSCI is characterised by tongue weakness
16	definition	dysphagia	oromotor function	Dysphagia in CSCI is characterised by velopharyngeal (soft palate) weakness
17	definition	dysphagia	laryngeal function	Dysphagia in CSCI is characterised by a weak voice
18	definition	dysphagia	laryngeal function	Dysphagia in CSCI is characterised by a wet sounding voice.
19	definition	dysphagia	laryngeal function	Dysphagia in CSCI is characterised by coughing after drinking or eating.
20	definition	dysphagia	laryngeal function	Dysphagia in CSCI is characterised by food or fluid coming out of the tracheostomy tube after eating.
21	definition	dysphagia	laryngeal function	Dysphagia in CSCI is characterised by food or fluid being aspirated into the lungs.
22	definition	dysphagia	pharyngeal function	Dysphagia in CSCI is characterised by difficulty of food or fluid passing from the mouth to the oesophagus.

23	definition		pharyngeal function	Dysphagia in CSCI can be characterised by delayed swallow initiation.
24	definition	dysphagia	laryngeal function	Dysphagia in CSCI can be characterised by reduced laryngeal elevation.
25	definition	dysphagia	laryngeal function	Dysphagia in CSCI can be characterised by impaired laryngeal sensation.
26	definition	dysphagia	laryngeal function	Aspiration risk secondary to dysphagia in CSCI is increased without protection of an effective cough
27	definition	dysphagia	laryngeal function	Dysphagia in CSCI can be characterised by an absent cough reflex.
28	screening	spinal cord injury	intubation	If a CSCI patient has a prolonged intubation (>48 hours) this will affect normal laryngeal function
29	screening	spinal cord injury	tracheostomy	If a CSCI patient has a tracheostomy in situ, this will affect normal laryngeal function
30	screening	spinal cord injury	ventilation	If a CSCI patient needs invasive ventilation, this will affect normal laryngeal function
31	screening	spinal cord injury	ventilation	If a CSCI patient needs non-invasive ventilation this will affect laryngeal function.
32	screening	spinal cord injury	tracheostomy cuff	If a CSCI patient has the cuff inflated on the tracheostomy tube, this will affect normal laryngeal function
33	screening	screening	position	Having to lie in supine for prolonged periods can make swallowing unsafe
34	screening	screening	tools	Dysphagia in CSCI is assessed by looking at oral-motor function on command.
35	screening	screening	laryngeal function	Dysphagia in CSCI is assessed by looking at laryngeal elevation when eating and drinking.
36	screening	screening	laryngeal function	Dysphagia in CSCI is assessed by looking at laryngeal sensation when eating and drinking.
37	screening	screening	laryngeal function	Dysphagia in CSCI is assessed by the loudness of the voice produced.
38	screening	screening	saliva	Dysphagia in CSCI is assessed by looking at how effectively oral secretions are managed by the patient.
39	screening	screening	oral trial	Dysphagia in CSCI is assessed by giving a swallowing trial of water to see if the patient coughs.
40	screening	screening	oral trial	Dysphagia in CSCI is assessed by giving a swallowing trial of yoghurt to see if the patient coughs.
41	screening	screening	oral trial	Dysphagia in CSCI is assessed by using blue dye in food or fluids to see if the patient aspirates.
42	screening	screening	respiratory	If a CSCI patient has deteriorating respiratory function, this can make swallowing unsafe.
43	screening	screening	respiratory measure	If a CSCI patient has a forced vital capacity (FVC) below one litre, this can make swallowing unsafe.
44	screening	screening	respiratory measure	If a CSCI patient has a reduced Forced Expiratory Volume in 1 second (FEV1) this can make swallowing unsafe.
45	assessment	instrumental	diagnostic	Videofluoroscopy is the best instrumental assessment to diagnose dysphagia in CSCI
46	assessment	instrumental	diagnostic	Flexible nasendoscopy is the best instrumental assessment to diagnose dysphagia in CSCI.

47	assessment	instrumental	bedside	Clinical bedside evaluation is the best instrumental assessment to diagnose dysphagia in CSCI.
48	assessment	position	upright	Dysphagia in CSCI is best assessed when the patient can be sat upright.
49	assessment	clinical sign	aspiration	Evidence the patient has aspirated is the only way to demonstrate dysphagia in CSCI
50	identification	clinical sign	suction	Evidence of dysphagia is suctioning food and/or fluids via tracheal suction
51	identification	clinical sign	pyrexia	Spiking pyrexia can be evidence of dysphagia
52	identification	clinical sign	chest infection	A chest infection can be evidence of dysphagia.
53	identification	clinical sign	suction	Increased frequency of oral suction via yankeur can be evidence of dysphagia.
54	identification	clinical sign	nutritional measure	A serum albumin value of <3.5g/dl can suggest nutritional problems relating to dysphagia
55	identification	clinical sign	nutritional measure	A serum pre-albumin level of < 15 mg/ml can suggest nutritional problems relating to dysphagia
56	management	swallowing	eat	Patients with a CSCI should be allowed to eat until there is evidence of a swallowing problem.
57	management	swallowing	NBM	Patients with a CSCI should be kept nil by mouth until assessed for evidence of a swallowing problem
58	management	swallowing	drink	Patients with a CSCI should be allowed to drink thin fluids unless there is evidence of a swallowing problem.
59	management	swallowing	diet modification	Patients with a CSCI should drink thickened fluids if there is evidence of a swallowing problem
60	management	swallowing	cough	Patients with a CSCI should be stopped from eating and drinking if they demonstrate consistent coughing.
61	management	nutrition	NG	Patients with a CSCI should be fed via NG tube initially if swallow is unsafe and nutrition is to be maintained.
62	management	nutrition	PEG	Patients with a CSCI should have a gastrostomy tube if problems persist for more than 4-6 weeks
63	management	tracheostomy	cuff	Patients with a CSCI should have tracheostomy cuff deflated when taking oral intake to reduce risk of aspiration
64	management	ventilation	NBM	Patients with a CSCI requiring 24 hour ventilation should not eat to reduce risk of aspiration
65	management	ventilation	NBM	Patients with a CSCI should only eat when they are off ventilation to reduce risk of aspiration
66	management	ventilation	weaning	Patients with a CSCI and dysphagia cannot be safely weaned off mechanical ventilation.
67	management	ventilation	speaking valve	Patients with a CSCI and dysphagia should not use in-line speaking valves.
68	management	position	supine	Patients with a CSCI should be allowed to eat when lying in a supine position.
69	management	position	semi-recumbent	Patients with a CSCI should be allowed to eat in a semi-recumbent/30 degree position.
70	management	position	upright	Patients with a CSCI should only be allowed to eat when they are in an upright position.
71	management	oral hygiene	VAP	Patients with a CSCI are at high risk of ventilator-associated pneumonia due to their supine position.

72	management	oral hygiene	VAP	Patients with a CSCI require regular oral hygiene to reduce the risk of ventilator-associated pneumonia.
73	management	mouthcare	dry mouth	Patients with a CSCI experience a dry mouth due to the effects of medication.
74	management	mouthcare	moisturise	Patients with a CSCI require regular moisturising of the oral mucosa to alleviate a dry mouth.
75	management	mouthcare	hydrate	Patients with a CSCI need regular sips of water to relieve a dry mouth.
76	management	communication	aids	Acute CSCI patients should use alternative communication aids to communicate effectively.
77	management	communication	voice	Acute CSCI patients should use their own voice to communicate effectively.
78	management	gastrointestinal	NBM	If a CSCI patient has a paralytic ileus they should be kept nil by mouth until it resolves.
79	therapeutic intervention	swallowing	eating	The goal of therapy is for the CSCI patient to return to safe eating and drinking.
80	therapeutic intervention	communication	voice	The goal of therapy is to help the patient with CSCI to communicate through talking.
81	therapeutic intervention	swallowing	therapy	CSCI patients with dysphagia benefit from daily swallow therapy to improve swallow safety
82	therapeutic intervention	swallowing	cuff	The goal of swallow therapy is to prevent aspiration by keeping tracheostomy cuff inflated whilst eating.
83	therapeutic intervention	swallowing	NBM	The goal of swallow therapy is to prevent aspiration by keeping the CSCI patient nil by mouth and fed enterally via tube.
84	therapeutic intervention	respiratory	self-ventilation	The goal of team intervention is for the CSCI patient to be able to self-ventilate without a tracheostomy.
85	therapeutic intervention	swallowing	no-change	Dysphagia in CSCI is a permanent state and is unlikely to improve.

Appendix 15 Invite to participate in expert panel

Dear colleague,

The DAISY project is a PhD study, which aims to develop of a screening tool to improve the identification of swallowing problems following acute cervical spinal cord injury. The project is now half-way though its 3 year timescale and is looking for experts to join the next stage of the study.

The work done so far

After carrying out an extensive literature review on the impact of spinal cord injury and our interventions (surgery, tracheostomy, positioning etc.) on the functions of the larynx and pharynx, a survey was developed to capture current practice in the UK. An online survey was sent out to professionals working in major trauma centres and intensive care units to find out about their current clinical practice in managing acute cervical spinal cord injury patients with regards to respiratory function, feeding, communication and mouthcare. Recently, I have interviewed patients about their own early experiences in the acute setting and the impact of clinical decisions on their lives. I hope to publish these results next year.

What happens next?

The next stage of my study aims to seek expert consensus on what affects swallowing, how it presents and ways to manage it effectively as this is a complex area that literature and current practice does not agree on. The value of gaining agreement from professionals who are working in this area, will make the output robust and generalisable. Based on your responses, I plan to develop a screening tool or checklist for multi-disciplinary staff in the acute setting, in order to highlight risks for dysphagia, reducing complications and mortality. This will allow further diagnostic assessments to be made with therapeutic interventions to permit safe oral intake. The tool will be piloted for usability and validity, and will be freely available.

Current work

I require upto 30 experts from various professions who have clinical experience in the field of acute cervical spinal cord injury (CSCI). I appreciate that this may be on an ad hoc or part-time basis due to variations in admission numbers in different units. This is an international invitation going out to colleagues in Australia, New Zealand, Canada, USA, UK and Europe. If you know of someone who might be a suitable addition to the panel, please feel free to nominate them by providing me with their email details.

Inclusion criteria

The following inclusion criteria will be used to assess expert status:

1. At least 3 years working in a clinical role with acute CSCI.
2. A member of one of the following professions: Doctor, Nurse, Physiotherapist, Dietitian or Speech and Language Therapist
3. Have experience of complex team decisions with regards to dysphagia.

You will be asked to provide the following details:

- Current site and country of working
- Qualification
- Profession
- Age bracket
- Gender
- Contact details (2 emails, 2 phone numbers and a fax number, just in case of catastrophic email failure)

I have attached a flow-chart and participant information sheet.

A modified Delphi method will be used to carry out the consensus process, using a company called the Delphi Process Research Unit who will coordinate and record contact details and responses electronically ensuring anonymity. A set of statements have been synthesised from the literature and the survey of clinical practice. This will be sent to you following your agreement to be involved. I am asking for a commitment to participate in upto 4 rounds of online questionnaire, although usually this is 2-3. Each

round is derived from from the results of the previous questionnaire, so the list reduces until a set of consensus statements emerge.

In return, I can offer future authorship on a publication about the process. Further details of the process will be sent once you have agreed to be involved.

If you agree to be involved please respond to this email by **MONDAY 16th NOVEMBER,** as this will allow the first round to be done before Christmas.

This work has been approved by the Project Evaluation Panel of the Royal National Orthopaedic Hospital Trust and is funded by the National Institute of Health Research as part of a Clinical Doctoral research Fellowship.

Please contact me directly if you have any queries.

Best wishes

Jackie McRae

Appendix 16 Expert panel demographic and consent form

Demographic and Consent form

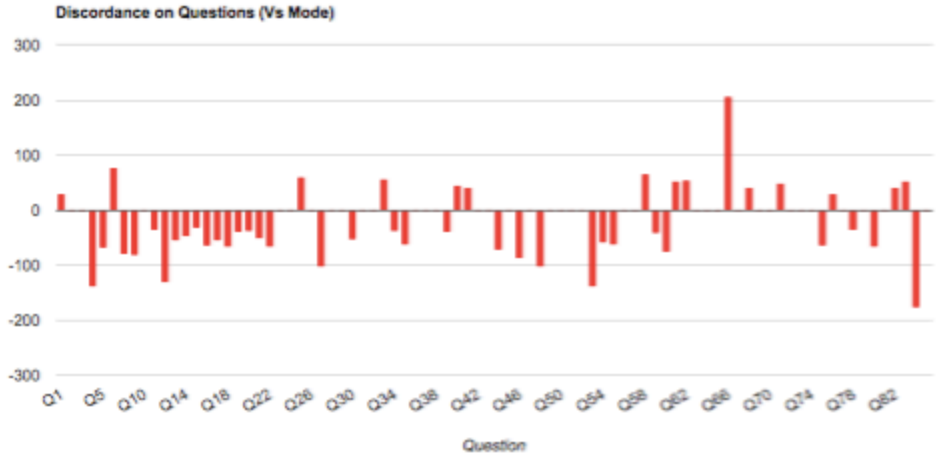
Name	
Present job title	Profession
Department	Qualifications
Employing organisation	Country
Background details:	
Male ☐	Age 18-24 ☐
Female ☐	25-34 ☐
	35-44 ☐
	45-54 ☐
	55-64 ☐
	over 65 ☐
Please list the number of years since qualification:	
Please list the number of years worked in spinal cord injury:	
Please detail the type of unit(s) you have had experience in SCI:	Intensive care unit ☐ Major trauma centre ☐ Spinal injury unit ☐ Other ☐ Details:
Contact details: *(this will be primarily via email, other contacts taken in case of problems)*	
Preferred email	
Second email	
Phone number 1	
Phone number 2	
Fax number	
Would you like to be listed as an author on the study publication using the above details? Yes ☐ No ☐	

Appendix 17 Sample of feedback report to expert panellist

Key Panelist Metrics

name	answer_label	count(*)
[redacted]		32
[redacted]	Agree	25
[redacted]	Agree Strongly	12
[redacted]	Disagree	25
[redacted]	Disagree Strongly	9
[redacted]	Neutral	13

Discordance compares the panelist's own responses with the mode of the panel as a whole and multiplies the difference by the percentage of the panel holding the modal view. ie. more agreeing to the mode view but me disagreeing gets a high score.



Cross Reference Code to Answer

Score	Choice
1	Disagree Strongly
2	Disagree
3	Neutral
4	Agree
5	Agree strongly

Appendix 18 Demographic of Delphi expert panel

Partic-ipant no.	Country	Gender	Profession	Age range	Year qualified	Years SCI experience	Unit experience	Co author agreement
1	Australia	female	SLT	35-44	16	10	ICU, MTC, SIU	yes
2	Australia	female	dietitian	25-34	6	5	ICU, MTC, SIU	yes
3	Australia	female	PT	45-64	30	20	ICU, SIU	yes
4	Australia	female	nurse	35-44	16	15	ICU, MTC, SIU	yes
5	Australia	female	SLT	35-44	12	11	ICU, SIU	yes
6	Australia	male	dietitian	35-44	16	5	ICU, SIU	yes
7	Ireland	female	SLT	25-34	9	7	ICU, SIU	yes
8	New Zealand	female	SLT	35-44	18	15	ICU	yes
9	New Zealand	female	SLT	45-64	40	25	ICU, SIU	yes
10	UK	male	doctor	45-64	25	20	MTC	yes
11	UK	female	doctor	45-64	20	3	SIU	yes
12	UK	male	doctor	65+	42	29	SIU	no
13	UK	female	PT	35-44	18	12	ICU, SIU	yes
14	UK	female	SLT	45-64	27	6	ICU, SIU	yes
15	UK	female	PT	35-44	15	7	ICU, MTC, SIU	yes
16	UK	female	PT	35-44	18	10	ICU, MTC, SIU	no
17	UK	female	nurse	45-64	33	6	ICU, MTC, SIU	yes
18	UK	female	PT	35-44	23	14	ICU, SIU	yes
19	UK	female	PT	45-64	28	21	SIU	no
20	UK	male	doctor	35-44	13	5	ICU, MTC, SIU	yes
21	UK	female	nurse	45-64	27	25	ICU, MTC, SIU	yes
22	UK	male	doctor	45-64	34	25	ICU, SIU	yes
23	UK	male	doctor	45-64	21	19	SIU	yes
24	UK	female	PT	35-44	15	10	ICU, MTC	yes
25	UK	female	SLT	25-34	8	3	ICU, SIU	yes
26	UK	female	PT	35-44	17	3	ICU, MTC, SIU	yes
27	USA	female	SLT	45-64	28	26	ICU, MTC, SIU	yes

Abbreviations: PT-physiotherapist; SLT-speech and language therapist; ICU-intensive care unit; MTC-major trauma centre; SIU-spinal injury

DPRU Communication 25 November 2015

Dear Ms Jackie McRae,

Introduction to the DAISY project Delphi process

Welcome to the first round of the DAISY project Delphi survey.

Please complete by Wednesday 13th January.

The purpose of this study is to gain consensus amongst international experts about the optimum way to screen, identify and manage swallowing problems in patients following an acute cervical spinal cord injury (CSCI).

Dysphagia is reported to occur in approximately 40% of cervical spinal cord injury patients. Although the numbers are often small, the complexity is high and swallowing problems contribute to worsening respiratory status, prolonging ventilator requirements and ICU stay. There is surprisingly little research on the optimum way to identify dysphagia in this patient group. This Delphi study aims to bring together expert knowledge and opinion to bridge the information gap.

The Delphi method achieves this by asking each participating expert to vote on how strongly they agree or disagree with each statement. The individual voting remains confidential but averages are used decide which statements are supported by a consensus of the participating experts.

Why does this matter?

We have provided you a link to the DPRU web-site to complete your Delphi survey. It is important that you understand the philosophy behind how a Delphi Study works in order for you to complete the survey properly.

“insert surveyurl:25”

Remember that the study is not interested in what you know about other people’s opinions, or what you have seen written down by other people in guidelines or in published papers: it is interested only in what you, as an expert, think in private about each of the statements presented in this survey.

How does the survey work?

The survey is made up of 85 statements presented over 7 pages.

Each question has 3 parts:

- A short statement for you to read
- A 5 point Likert scale for you to select how strongly you agree or disagree with the statement
- A free text box for you to write any comments you wish to make about the wording or content of the statement

Appendix 19 Delphi round one invitation and survey link

How long do I have to complete the survey?

- ***The latest deadline for having completed the survey is Wednesday 13th January, but you can complete it in advance.***
- How long you spend completing the survey is up to you.
- Most people complete Delphi surveys quite quickly, but some spend a lot of time writing comments on statements they feel strongly about.
- Comments are important for the process because when there is no clear consensus this allows the statement to be improved and tested again in a second round of voting.

If you need technical support because you have had problems using the DPRU on-line system you can get help by

- Sending an e-mail about the problem to XXXXXX

We hope you enjoy using the DPRU on-line system and find the Delphi Questionnaire interesting to complete.

Jackie McRae XXXXXXXXXXX XXXXXXXX

DAISY project investigator Delphi Facilitator Technical Director

The DAISY project Delphi process is supported by the DPRU

Round 1 Statement no.s	N Valid	Missing	Mean	Median	Mode	Std. Deviation	Range	Percentiles		
								25	50	75
Q1	27	0	3.19	3.00	3a	1.075	4	2.00	3.00	4.00
Q2	27	0	3.96	4.00	4	.706	3	4.00	4.00	4.00
Q3	27	0	3.78	4.00	4	.892	3	3.00	4.00	4.00
Q4	27	0	3.67	4.00	4	.734	3	3.00	4.00	4.00
Q5	27	0	4.56	5.00	5	.892	4	4.00	5.00	5.00
Q6	25	2	4.04	4.00	4	.841	3	3.50	4.00	5.00
Q7	26	1	2.62	3.00	2a	.852	3	2.00	3.00	3.00
Q8	27	0	3.56	4.00	4	1.086	4	3.00	4.00	4.00
Q9	25	2	3.40	4.00	4	1.041	4	3.00	4.00	4.00
Q10	27	0	4.52	5.00	5	.643	2	4.00	5.00	5.00
Q11	27	0	3.33	3.00	3a	.877	3	3.00	3.00	4.00
Q12	27	0	4.07	4.00	5	1.107	4	4.00	4.00	5.00
Q13	27	0	1.93	2.00	2	.874	4	1.00	2.00	2.00
Q14	27	0	1.96	2.00	2	.808	3	1.00	2.00	2.00
Q15	27	0	2.59	2.00	2	1.248	4	2.00	2.00	4.00
Q16	27	0	2.89	3.00	3	1.219	4	2.00	3.00	4.00
Q17	27	0	3.63	4.00	4	.742	3	3.00	4.00	4.00
Q18	27	0	3.89	4.00	4	.577	2	4.00	4.00	4.00
Q19	27	0	3.63	4.00	4	1.214	4	2.00	4.00	5.00
Q20	26	1	3.77	4.00	4	1.210	4	3.00	4.00	5.00
Q21	27	0	4.41	4.00	4	.572	2	4.00	4.00	5.00
Q22	27	0	4.04	4.00	4	.759	3	4.00	4.00	4.00

Q23	27	0	3.70	4.00	4	.869	3	3.00	4.00	4.00
Q24	27	0	4.15	4.00	4	.602	2	4.00	4.00	5.00
Q25	27	0	4.26	4.00	4	.594	2	4.00	4.00	5.00
Q26	27	0	4.41	5.00	5	.797	3	4.00	5.00	5.00
Q27	27	0	3.70	4.00	4	1.137	4	3.00	4.00	4.00
Q28	27	0	3.89	4.00	4	.698	3	4.00	4.00	4.00
Q29	27	0	3.93	4.00	4	.917	3	4.00	4.00	5.00
Q30	27	0	4.07	4.00	4	.781	3	4.00	4.00	5.00
Q31	27	0	2.93	3.00	2a	.874	3	2.00	3.00	4.00
Q32	27	0	4.15	4.00	4	.662	2	4.00	4.00	5.00
Q33	27	0	3.48	4.00	4	.935	4	3.00	4.00	4.00
Q34	26	1	3.12	3.00	4	1.033	4	2.00	3.00	4.00
Q35	25	2	3.68	4.00	4	.852	4	3.00	4.00	4.00
Q36	25	2	3.76	4.00	4	.879	3	3.00	4.00	4.00
Q37	25	2	2.88	3.00	2	.971	3	2.00	3.00	4.00
Q38	27	0	3.93	4.00	4	.616	3	4.00	4.00	4.00
Q39	27	0	2.93	3.00	4	1.035	3	2.00	3.00	4.00
Q40	27	0	2.59	2.00	2	1.010	3	2.00	2.00	4.00
Q41	27	0	2.44	2.00	2	1.155	3	2.00	2.00	4.00
Q42	26	1	4.27	4.00	4	.724	3	4.00	4.00	5.00
Q43_	27	0	3.33	3.00	2	1.144	3	2.00	3.00	4.00
Q44	27	0	3.22	3.00	4	.974	3	2.00	3.00	4.00
Q45	26	1	3.15	3.00	2a	1.255	4	2.00	3.00	4.00
Q46	27	0	3.63	4.00	4	1.182	4	3.00	4.00	4.00
Q47	27	0	2.26	2.00	2	1.095	4	2.00	2.00	3.00
Q48	27	0	3.22	4.00	4	1.050	4	2.00	4.00	4.00

Q49	27	0	1.78	2.00	2	.801	3	1.00	2.00	2.00
Q50	27	0	4.04	4.00	4	.980	4	4.00	4.00	5.00
Q51	27	0	3.63	4.00	4	.926	3	3.00	4.00	4.00
Q52	27	0	3.81	4.00	4	.736	3	4.00	4.00	4.00
Q53	27	0	3.59	4.00	4	.844	3	3.00	4.00	4.00
Q54	27	0	3.04	3.00	3	.940	4	3.00	3.00	3.00
Q55	27	0	3.07	3.00	3	.616	2	3.00	3.00	3.00
Q56	26	1	2.19	2.00	1	1.132	3	1.00	2.00	3.00
Q57	27	0	3.41	4.00	4	1.083	3	2.00	4.00	4.00
Q58	27	0	2.56	2.00	2	1.086	3	2.00	2.00	4.00
Q59	26	1	2.35	2.00	2	1.129	4	1.75	2.00	3.00
Q60	26	1	3.58	4.00	4	1.027	3	3.00	4.00	4.00
Q61	27	0	4.48	4.00	4	.509	1	4.00	4.00	5.00
Q62	26	1	3.92	4.00	4	1.017	4	4.00	4.00	5.00
Q63	26	1	3.69	4.00	5	1.408	4	2.75	4.00	5.00
Q64	25	2	2.04	2.00	2	.935	3	1.00	2.00	2.00
Q65	27	0	2.04	2.00	2	.854	3	2.00	2.00	2.00
Q66	27	0	1.78	1.00	1	1.086	4	1.00	1.00	2.00
Q67	27	0	1.85	2.00	2	.718	2	1.00	2.00	2.00
Q68	27	0	2.89	3.00	2	1.188	4	2.00	3.00	4.00
Q69	27	0	3.70	4.00	4	.869	3	3.00	4.00	4.00
Q70	27	0	2.44	2.00	2	1.155	4	2.00	2.00	3.00
Q71	27	0	3.37	4.00	4	1.006	4	3.00	4.00	4.00
Q72	26	1	4.35	5.00	5	.936	4	4.00	5.00	5.00
Q73	25	2	4.08	4.00	4	.702	2	4.00	4.00	5.00
Q74	27	0	4.19	4.00	4	.681	2	4.00	4.00	5.00

Q75	27	0	3.15	3.00	3	1.064	4	2.00	3.00	4.00
Q76	27	0	3.52	4.00	4	1.087	3	3.00	4.00	4.00
Q77	27	0	4.07	4.00	4	.829	3	4.00	4.00	5.00
Q78	27	0	3.96	4.00	4	.940	3	3.00	4.00	5.00
Q79	27	0	4.56	5.00	5	.892	3	4.00	5.00	5.00
Q80	27	0	4.44	5.00	5	1.013	4	4.00	5.00	5.00
Q81	25	2	4.20	4.00	4a	.764	2	4.00	4.00	5.00
Q82	27	0	1.96	2.00	1	1.055	3	1.00	2.00	2.00
Q83	27	0	1.74	1.00	1	.944	3	1.00	1.00	2.00
Q84	27	0	4.00	4.00	5	1.177	4	3.00	4.00	5.00
Q85	27	0	1.37	1.00	1	.492	1	1.00	1.00	2.00

Daisy Delphi Panel Round 1 Summary Report

Introduction to the Daisy Delphi

As a variety of practices have been reported in the identification and management of dysphagia in CSCI, with very little specific data, an expert consensus panel was sought using the Delphi method to collect expert opinions.

This study employed a modified Delphi approach, generating 90 statements from the literature review and a staff survey on current practice in UK. The statements were categorised into seven areas: co-morbid status, definition, screening, assessment, identification, management and therapeutic intervention (see spidergram).

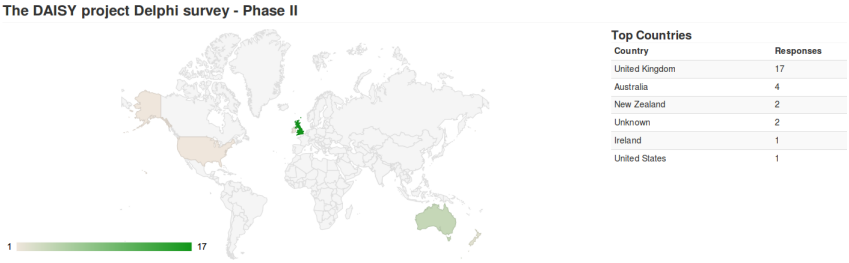
A steering group made up of two doctors, a speech and language therapist and a physiotherapist oversaw and agreed each round. The steering group voted to discard 5 statements, rephrase 37 and keep 48.

The 85 statements were then distributed to the expert panellists, who were asked to rate each statement using a 5 point Likert scale (disagree strongly, disagree, neutral, agree, agree strongly) and a free text box was available for additional comments

The researchers looked at both the quantitative and the qualitative aspects of the feedback.

The First round Delphi Questionnaire was completed by 27 Members of the Expert Panel distributed in countries described below.

Figure 1: Distribution of panellists



Top Countries

Country	Responses
United Kingdom	17
Australia	4
New Zealand	2
Unknown	2
Ireland	1
United States	1

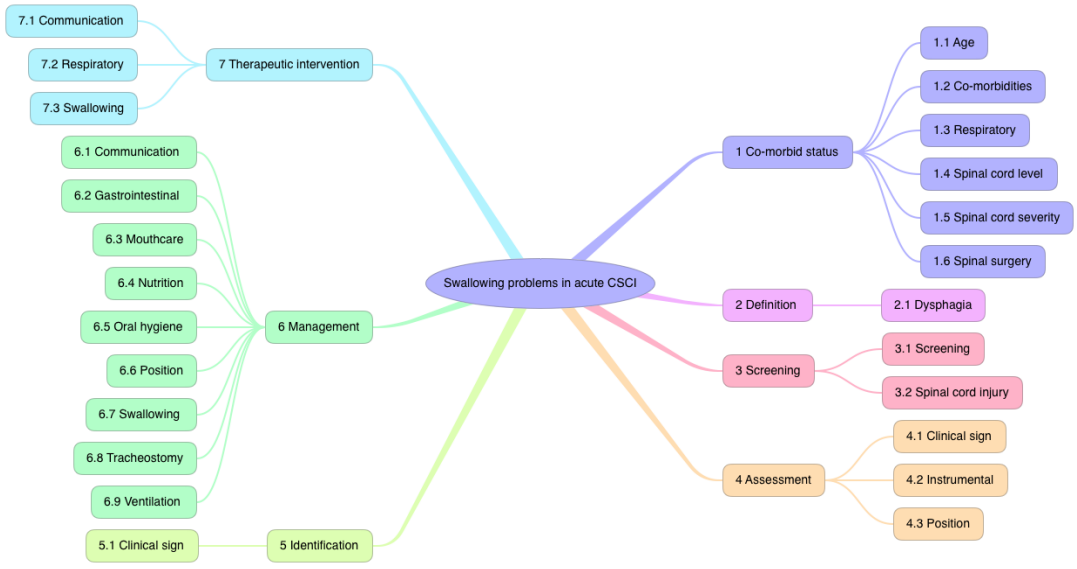
27 expert professionals consented to their involvement and they all completed the first round. The expert panel was made up of 8 physiotherapists, 8 speech and language therapists, 6 doctors, 3 nurses and 2 dietitians. They were mostly from the UK, but included participants from Australia, New Zealand, USA and Ireland.

A minimum of 3 years experience working in SCI was requested and the range went up to 29 years.

Figure 2: Spidergram chart of surveyed Domains

The Spidergram chart was developed to categorise the data collected during the open questionnaire and concurrent research.

The key domains were considered to be Comorbidity, Screening, Assessment, Classification, Management and Therapeutic intervention with subdomains that assisted in the creation of questions to be put to the team.

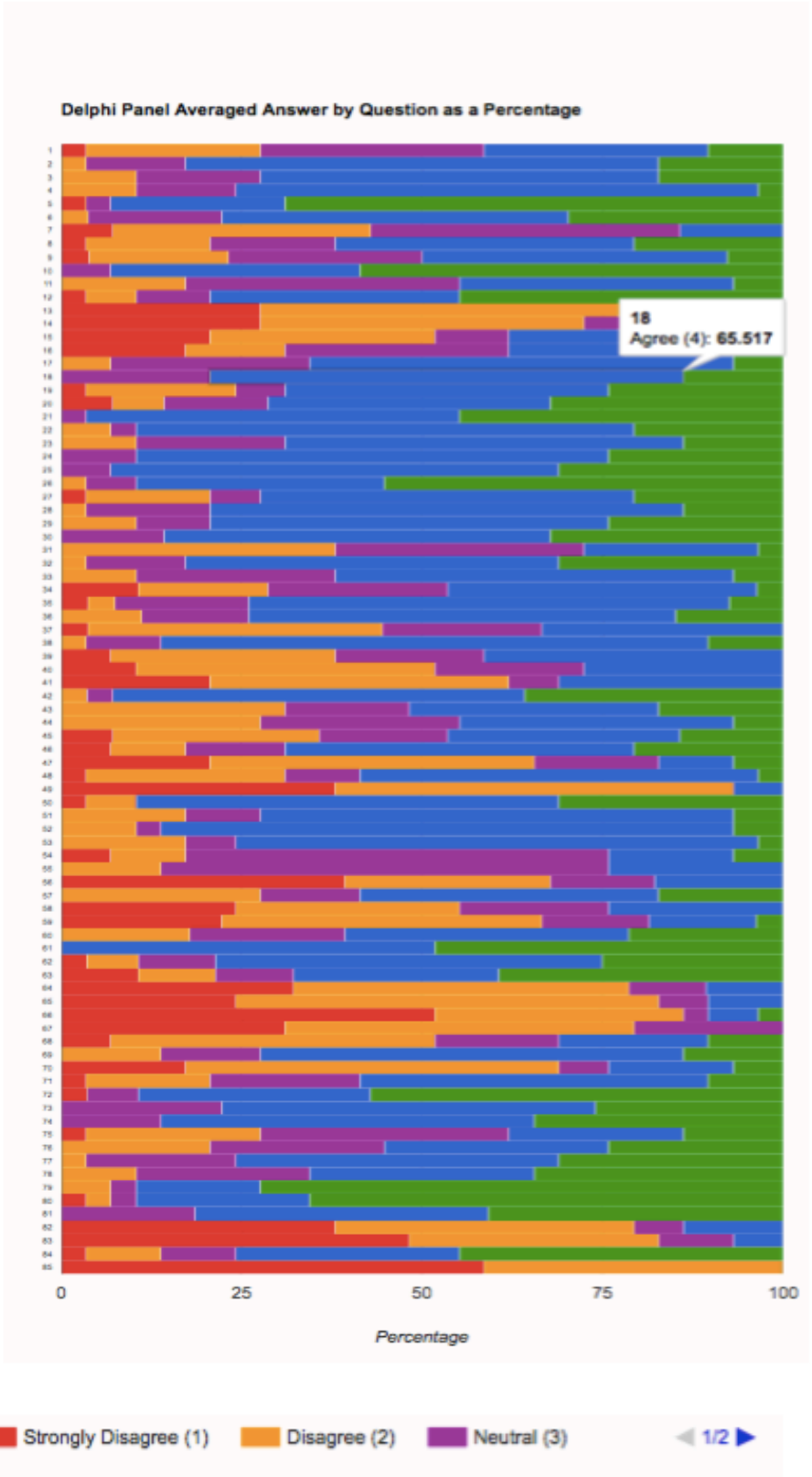


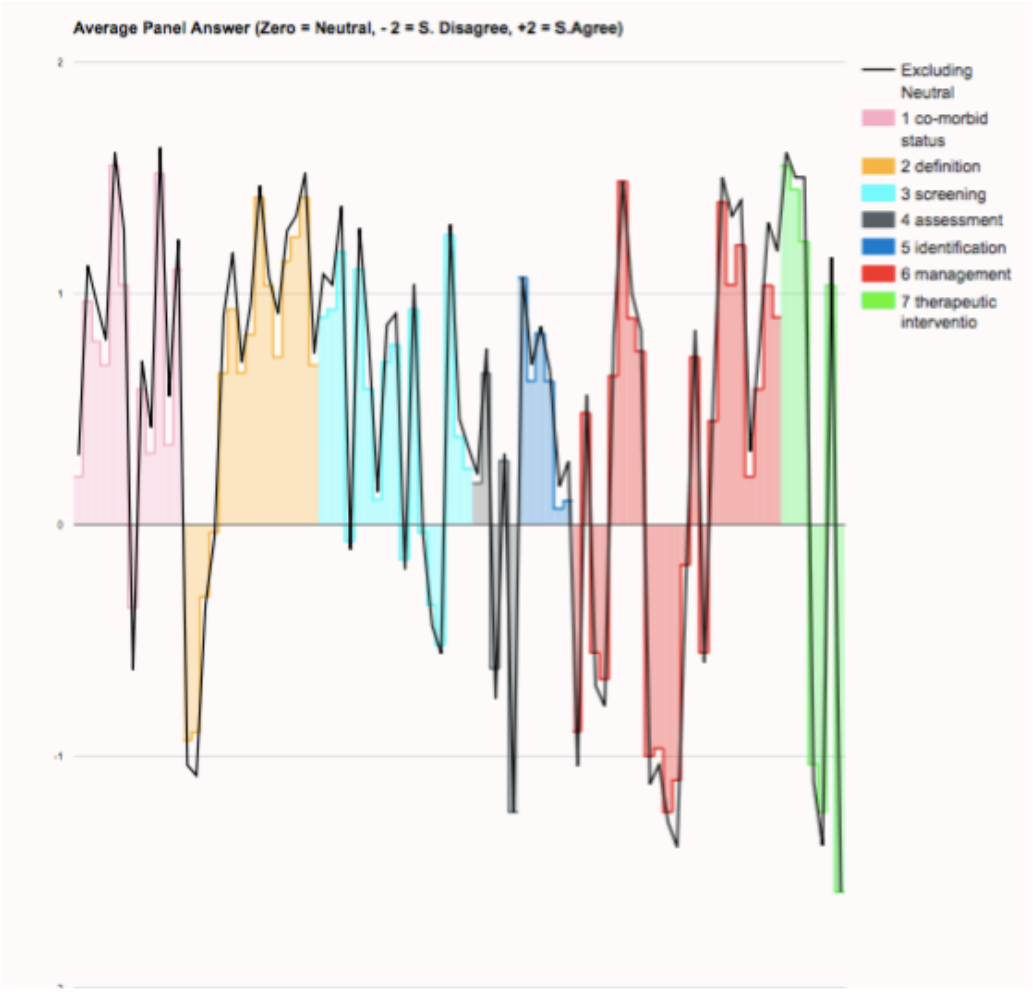
The following graph shows how the votes were distributed for each question – the length of the different coloured bars represents the percentages of votes in each category for each question.

The Key at the bottom represents the colours of the voting with Strongly Disagree (to the left) through to Strongly Agree (To the Right).

It is possible to see at a glance the proportion of views and by moving your mouse over the graphic you can identify quickly the question and the proportion of votes allocated.

Figure 3: Graph of Votes by Answer & Question





Because the questions were numbered in order by the domain / characteristic of dysphagia following acute CSCI, the graph gives a visual indication of where the expert panel agreed that the topic was of high relavance and where it was not – and also how relevant it was.

Interpretation & Comments

Each panellist had the opportunity to comment alongside their response. In order to determine if there were any issues with the statements supported by a consensus, the comments recorded against each question were reviewed.

The comments on the statements supported by a positive consensus, suggest that the wording of the some of the statements could be improved but did not suggest that the panellists had been misled as to the meaning.

The comments on the statements supported by a negative consensus were few in number and tended only to reinforce the views supported by the consensus. A listing of

Preliminary findings

a. Experts agree that an associated brain injury, respiratory impairment, cervical spinal cord injury and anterior cervical spine surgery add complexity to the swallowing mechanism.

b. The definition of dysphagia in CSCI is agreed to include difficulty of food or fluid transmission, aspiration of food or fluid, wet voice, reduced laryngeal elevation and sensation, absent or weak cough. It is not defined by facial or lip weakness.

c. The need for a swallow screen should be considered after a prolonged intubation or tracheostomy, particularly if respiratory function is deteriorating or invasive ventilation is required with cuff inflated. Both laryngeal elevation and sensation should be screened, with oral secretion management providing information.

d. A clinical bedside swallow assessment is not seen as the best instrumental assessment. Although no agreement on what is.

e. Dysphagia may be identified by the presence of a chest infection, spiking pyrexia, increased suction either by mouth or via tracheostomy.

f. Nasogastric feeding is agreed to be important, with transition to gastrostomy if problems persist. Dry mouth is acknowledged with regular oral hygiene recommended. Upright was not mandatory and a semi-recumbent position was agreed to be acceptable when eating. Being ventilated should not restrict oral intake or use of speaking valves.

g. Therapy should avoid keeping patients nil by mouth with inflated tracheostomy cuffs and aim to return normal function for swallowing and communication, in addition to self-ventilation if possible. This should be achieved with daily therapy.

There was unanimous agreement that swallowing problems in CSCI do improve and this supports sensitive screening and assessment with focused interventions.

Next steps

The Steering Group were asked to review the results and advise the facilitator if any of the first round questions should be reworded and presented to the Panellists in a new questionnaire for a second round of voting.

Following this consultation, another round has been prepared for the expert panel.

Subsequent steps will include circulating the approved report to the whole panel for information and comment and the preparation of a draft version of a paper for publication based on the text and tables of the study report.

Appendix 22 Delphi round one results by profession

DELPHI R1 Statement no.	**Doctor n=6**		**NURSE n=3**		**PT n=8**		**SLT n=8**		**Dietitian n=2**	
	Average	Range	Average	Range	Average	Range	Average	Range	Average	Range
1	3	3	3.6	1	3	2	3.25	4	3.5	3
2	4	2	4.4	1	4.11	2	3.62	2	4	2
3	3.83	3	4	0	3.78	3	3.62	3	4	0
4	3.83	1	4.4	1	3. 44	2	3.5	2	4	0
5	4.83	1	5	0	4.44	2	4.12	4	5	0
6	3.83	3	4	0	4.37	2	3.87	2	4	0
7	2.5	3	2.8	2	2.87	2	2.37	1	2.5	3
8	3.33	3	3.2	2	3.56	4	3.75	3	4	0
9	3.5	3	3	2	3.14	4	3.37	2	3	2
10	4.67	1	4.8	1	4.67	1	4.37	2	3.5	1
11	3.17	2	4	3	3.33	3	3.25	2	3.5	1
12	4.17	2	5	0	4	3	3.75	4	4.5	1
13	2.17	1	2.8	2	2.33	4	1.37	1	2.5	1
14	2.33	1	2.8	2	2.33	3	1.37	1	2.5	1
15	2.5	2	3.2	2	3.11	4	1.62	3	4	0
16	3.33	3	3	2	3.22	4	2.12	3	3.5	1
17	3.67	3	4	0	3.44	1	3.75	3	3.5	1
18	3.83	1	4.4	1	3.78	2	3.87	2	4.5	1
19	4.17	2	4	3	2.89	3	3.75	3	5	0
20	4.17	2	4	3	3	4	4.12	2	5	0
21	4.33	1	4.8	1	4.33	2	4.25	1	5	0
22	4.17	1	4.4	1	3.89	3	3.87	3	4.5	1
23	4	2	4.4	1	3.78	3	3.12	2	4	2
24	3.83	2	4.4	1	4.11	2	4.25	1	4.5	1
25	3.67	1	4.4	1	4.44	1	4.37	1	4.5	1
26	4.5	1	4.8	1	4.56	2	4	3	5	0
27	3.5	3	4.4	1	3.44	2	3.37	4	5	0
28	4	0	4.4	1	3.89	2	3.5	3	4.5	1
29	4.33	1	4.4	1	3.89	3	3.37	3	4.5	1
30	4.5	1	4.8	1	4	2	3.86	2	4.5	1
31	3	3	2.4	1	3	2	3.12	2	2.5	1
32	4.33	1	4.8	1	4.22	2	3.5	3	4	0
33	3.5	2	3.6	1	3.44	3	3.5	1	4.5	1
34	2.83	2	4	0	3.56	2	2.12	3	4.5	1
35	3.5	2	4	0	3.89	1	3.29	4	4.5	1

36	2.83	2	4	0	4	2	4	2	4.5	1
37	2.67	3	2.8	2	2.87	2	2.86	2	2.5	1
38	3.83	1	4	0	4.11	2	3.75	3	4	0
39	2.83	3	3.6	2	2.67	3	2.87	2	4	0
40	2.33	3	2.4	3	2. 44	3	2.75	2	4	0
41	3.33	2	2.8	3	2.11	3	2.12	3	1.5	1
42	4.33	1	4.4	1	4.12	3	4.12	2	5	0
43	3	3	4.2	2	3.22	3	3.5	3	3.5	1
44	3	2	3.4	1	2.89	3	3.62	3	3.5	1
45	3.67	3	3.6	2	3.11	3	2.14	3	5	0
46	3.67	3	4	0	4.22	3	2.87	4	4	0
47	2.17	3	3.2	2	2.11	3	2.37	4	2	0
48	3.17	2	4	0	3.22	2	2.75	3	4.5	1
49	1.67	1	1.2	1	2.33	3	1.5	1	1.5	1
50	4.33	1	4	3	3.67	4	4.37	1	4.5	1
51	3.5	3	3.2	2	3.78	2	3.62	2	4.5	1
52	3.83	3	3.6	2	3.78	2	3.87	1	4.5	1
53	4.17	1	3.6	2	3.22	2	3.62	2	4	0
54	3.5	3	3.4	1	3.22	3	3	2	1	0
55	3.17	2	3.6	1	3.11	2	3	2	2.5	1
56	2.4	3	1.2	1	1.78	3	2.5	3	2.5	1
57	3	2	4.8	1	3.78	3	3.25	3	2.5	1
58	2.5	3	1.6	1	2.44	3	2.5	3	3.5	1
59	2.5	3	3.2	3	2.12	3	2	3	2	2
60	3.17	2	4.8	1	3. 22	2	4	2	4.5	1
61	4.5	1	4.8	1	4.33	1	4.37	1	5	0
62	3.67	3	2.8	3	4.37	2	4	2	4.5	1
63	3	3	3.2	4	4.67	2	3.86	3	3	4
64	2.4	3	1.6	1	2. 11	3	1.5	1	3.5	1
65	2.5	2	1.6	1	2.22	3	1.5	1	3	2
66	2.33	3	2	2	1.67	4	1.37	1	1.5	1
67	2.17	2	2.8	1	1.56	1	1.5	1	2.5	1
68	2.33	3	2.4	1	3.33	3	3.25	3	1.5	1
69	3.33	2	4.4	1	3.67	3	4	2	3	2
70	2.33	2	1.6	1	3	4	1.75	2	3.5	3
71	3.33	2	3.2	3	3.67	4	3.37	2	3.5	1
72	4.33	1	4.4	1	4.67	2	4	4	4.5	1

Appendix 22 Delphi round one results by profession

73	4.33	1	4.4	1	3.87	2	3.71	2	4.5	1
74	4.17	1	4.4	1	4.11	2	4.12	2	4.5	1
75	2.33	1	3.6	3	2.89	3	3.87	2	3.5	3
76	3.17	3	3.6	3	4	3	3.62	3	3	2
77	3.67	3	3.6	1	4	2	4.62	1	3.5	1
78	4	2	3.6	3	4.11	2	3.62	3	5	0
79	4.17	3	4.8	1	4.22	3	5	0	5	0
80	4	3	4.8	1	4.56	1	4.87	1	3	4
81	3.83	1	4.8	1	4.44	2	4.17	2	3.5	1
82	2.67	2	1.6	1	1.56	2	1.37	1	3.5	1
83	2.33	3	1.6	1	1.67	2	1.25	1	2	2
84	4	2	4.4	3	3.67	4	4.25	2	4.5	1
85	1.17	1	2	0	1.56	1	1.25	1	1	0
Average range		2.07		1.39		2.53		2.24		0.96

	Round 2 statements with statistical summary n=25	MEAN	SD	Median (IQR)	mode	% consensus
1	FEES (flexible endoscopic evaluation of swallowing) is better than videofluoroscopy for the assessment of swallowing in acute CSCI patients	3.81	1.059	4 (3-5)	4	65.4
2	Where possible, dysphagia is best assessed when the CSCI patient is upright	3.92	0.744	4 (3.75-4)	4	76.9
3	Coughing at mealtimes can be suggestive of dysphagia in CSCI patients	4.15	0.784	4 (4-5)	4	84.6
4	Advanced age is not a primary feature in determining dysphagia in CSCI	3.35	0.892	4 (2.75-4)	4	53.8
5	If a CSCI patient has posterior cervical spinal surgery, they may experience swallowing problems	3.54	0.948	4 2.75-4)	4	69.2
6	Patients with a CSCI should have tracheostomy cuff deflated when taking oral intake to reduce risk of aspiration	3.8	1.225	4 (3-5)	5	68
7	Dysphagia in CSCI can be characterised by coughing after drinking or eating.	3.85	0.834	4 (4-4)	4	80.8
8	CSCI can present with tongue weakness as a secondary feature	3.46	0.859	4 (3-4)	4	53.9
9	Oral-motor assessment can support an overall impression of dysphagia in CSCI	3.65	1.129	4 (3-4.25)	4	65.4
10	CSCI can present with velopharyngeal (soft palate) weakness as a secondary feature	3.4	0.866	3 (3-4)	4	48
11	A variety of food trials are useful in the assessment of swallowing in CSCI patients	4.16	0.746	4 (4-5)	4	88
12	If a CSCI patient has a complete spinal cord injury (AIS A) they will require a swallowing assessment	4.15	1.12	5 (3.75-5)	5	76.9
13	Thickened fluids reduce the risk of aspiration in CSCI patients with dysphagia	2.81	1.297	2.5 (2-4)	2	50
14	A sequential fall in serum albumin is an indicator of the impact of dysphagia on nutritional status	2.96	0.999	3 (2-4)	3	38.5
15	Patients with CSCI should eat and drink in their usual position, which may not be upright.	3.44	1.158	4 (3-4)	3	56
16	A sequential fall in FVC is a useful indicator of respiratory impairment affecting swallowing	3.81	0.895	4 (3-4.25)	4	65.4
17	CSCI patients should be allowed to eat rather than being kept NBM until a definitive swallow assessment is made.	2.27	1.041	2 (2-3)	2	73
18	Regular oral hygiene helps to reduce VAP in CSCI patients	4.46	0.761	5 (4-5)	5	92.3
19	Dysphagia in CSCI can be characterised by food or fluid coming out of the tracheostomy tube after eating.	4.08	0.891	4 (4-5)	4	80.8

20	Artificial saliva gels rather than fluids should be used to manage dry mouth in CSCI	3.58	0.809	4 (3-4)	4	53.8
21	CSCI can present with voice weakness as a secondary feature	4.16	0.374	4 (4-4)	4	100
22	A thoracic level injury with respiratory impairment may affect swallowing function	3.38	0.898	3.5 (3-4)	4	50
23	An incomplete SCI (AIS levels B to D) may have swallowing problems dependent on treatment or surgery	4.19	0.402	4 (4-4)	4	100
24	Non-invasive ventilation may disrupt swallowing function in CSCI patients	3.88	0.816	4 (3.75-4)	4	76.9
25	Dysphagia in CSCI can be characterised by delayed swallow initiation.	3.85	0.784	4 (3.75-4)	4	76.9

Appendix 24 Delphi round two summary report

Daisy Delphi Panel Round 2 Summary Report

Introduction to the Daisy Delphi

Following completion of Delphi round 1, the 35 statements that had not received consensus were reviewed by the steering group using panellists comments. Of these, 22 were re-phrased, 10 were discarded as they were similar or incorporated into other statements and 3 were kept and re-submitted as in the first round.

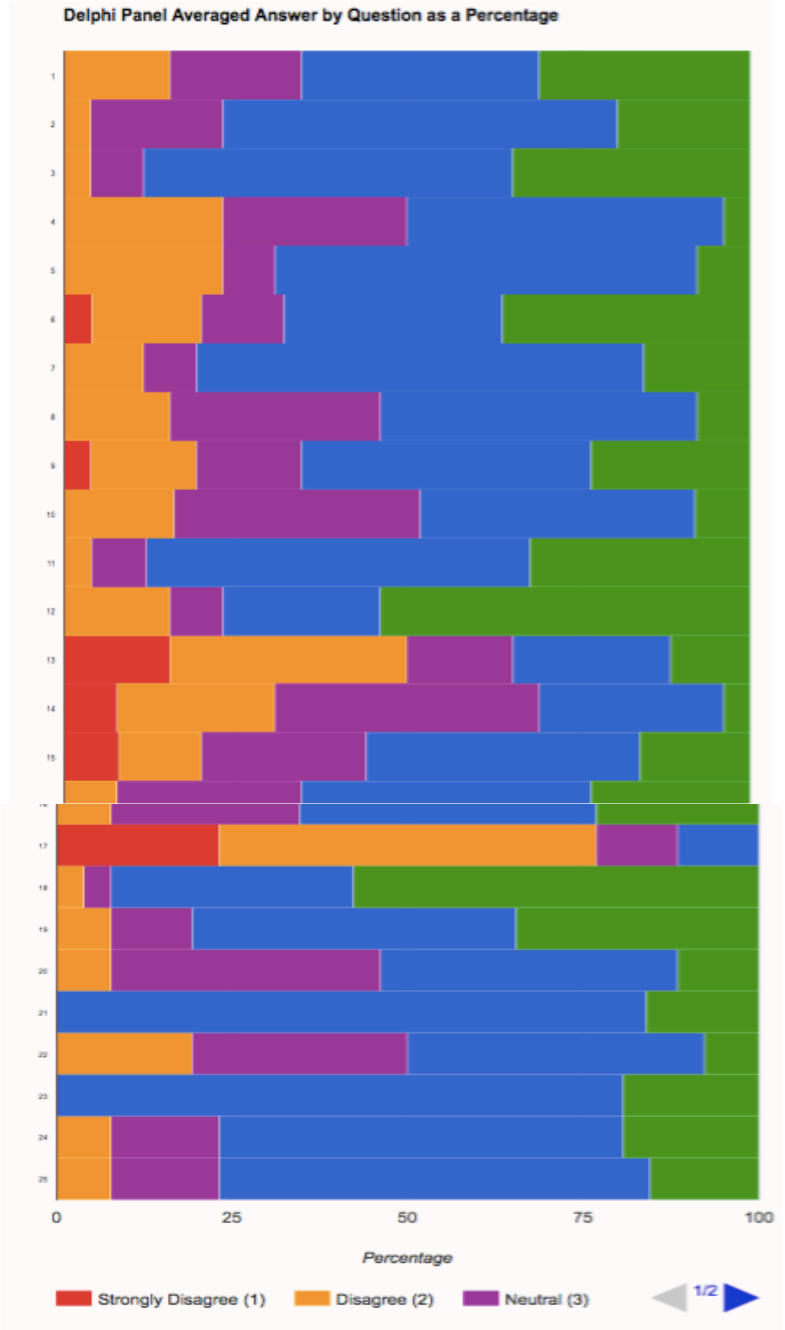
The remaining 25 statements were randomised in the second round to encourage voting for each item rather than within categories.

The same 5 point Likert scale was used selecting from disagree strongly to agree strongly with the option of free text comments.

In preparation for the second round, all panellists were given the opportunity to log into the dpru.org system and review reports on round 1 and their own performance compared to the group responses.

The summary report included demographic data, graphical representation of the responses, tables of results within categories and for each statement as well as comments.

This helped to inform individuals of the overall consensus which may have allowed panellists to consider changing their opinion in line with the group. This is a key feature of the Delphi technique.



Supporting Data

The number of votes in each category for each statement were also used to calculate how far the average result for each statement deviated from neutral weighting). If the weight for a statement fell more than 1 point above or below neutral the score indicated that a consensus was present.

Figure 4: Graph of Votes averaged by statement

Data is normalised around Neutral as Zero; Disagreement is Negative / Agreement is Positive.

The following graph shows how far the result for each statement diverged from neutral.

Explanation: Each domain (described above) and its statements is presented with the average votes for each from the panel. The peaks to the top of the chart reflect the statements moving to agreement and strong agreement. The valleys under the line reflect the statements on average receiving votes that average to disagree or strongly disagree. The band in the middle axis reflects statements that overall received a neutral score on average.

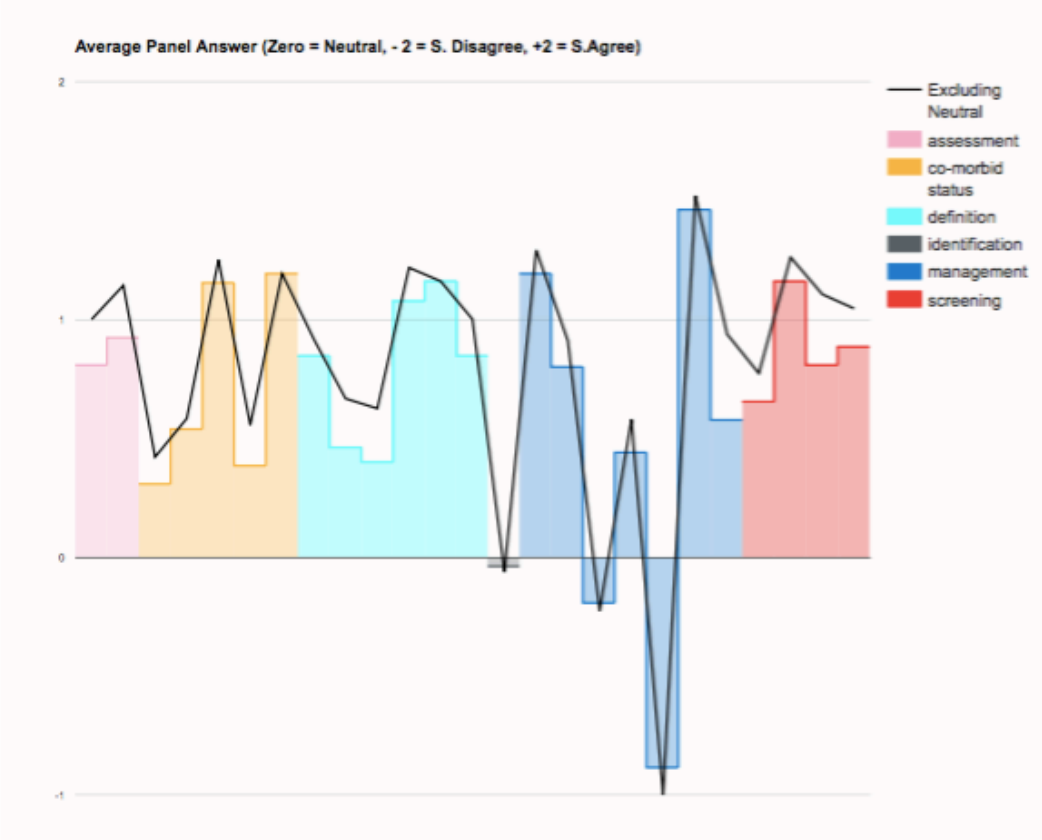
It is not possible without further questioning to establish whether neutral represents don't know , doesn't matter or not qualified to comment.

On that basis we thought it might be useful to add a secondary series to the graph which presents the data excluding the neutral answers to see how extensively the results would vary. There are a few statements that differ when neutral is removed, this moves them towards a greater agree or disagree. The only statement that remains in neutral is about serum albumin, which the majority of professionals voted neutral.

Key:

The coloured area reference the scores averaged including Not Sure / Neutral scores.

The Lines reflect the average scores excluding those Neutral / Not Sure votes.



The statements were randomised for round 2, so in this graph they have been regrouped by category. The graph gives a visual indication of where the expert panel agreed that the topic was of high relavance and where it was not – and also how relevant it was. Management of dysphagia appears to have mixed opinions, compared to definition, screening and assessment.

Interpretation & Comments

Each panellist had the opportunity to comment alongside their response. In order to determine if there were any issues with the statements supported by a consensus, the comments recorded against each statement were reviewed. These commments helped to clarify current practices and beliefs with regards to identifying and managing dysphagia. Some statements generated many commments and some none.

The comments on the statements supported by a positive consensus, suggest that the wording of the some of the statements could be improved but did not suggest that the panellists had been misled as to the meaning.

The comments on the statements supported by a negative consensus were few in number and tended only to reinforce the views supported by the consensus. A listing of all of the comments are available to the group in the detailed analysis.

On the second round, out of 25 statements 12 statements (48%) reached >70% consensus with a further 20% gaining majority agreement (>55%). Further review of the change in ranking between round 1 and round 2 helps to identify changes amongst members of the panel.

Consensus findings:

- Co-morbid status - complete and incomplete level injuries may have swallowing problems
- Definition – the presentation of dysphagia may include weak voice, coughing or choking with oral intake and food leaking from tracheostomy.
- Screening – non-invasive ventilation may disrupt normal swallowing.
- Assessment - a range of foods should be used to assess swallowing and where possible the patient should be assessed in an upright position
- Management – there was consensus that patients should not eat before a swallow assessment is made; coughing at meals was suggestive of dysphagia; oral hygiene was required to reduce VAP.

In this round there was unanimous agreement that an incomplete level injury may have an impact on swallowing and that voice weakness may be a secondary feautre.

Majority support (>55%) for:

- Posterior surgery may impact on swallowing
- an assessment of oral function can support a diagnosis of dysphagia
- a change in FVC could suggest potential risk for dysphagia
- FEES may provide a better assessment of swallowing compared to VFS
- Implementing tracheostomy cuff deflation for oral intake

Several areas did not reach a consensus of 70% or majority agreement. The items that do not gain consensus are as important as those that do.

- The panel did not agree that older age raises the risk of dysphagia or that a thoracic level injury impacts on swallowing.
- Tongue or soft palate weaknesses were not considered a feature of CSCI.
- Serum albumin were not considered a clinical indicator of malnutrition.
- The use of thickened fluids was not supported by all panellists, which may reflect different practices.
- The use of artificial saliva for dry mouth was not supported, although there was consensus from the first round to support mouth moisturising, this may reflect different practices.

These may be because of a lack of evidence on these areas or differences in local practice or between different professional groups. Further investigations of certain areas may be beneficial to help inform clinical practices.

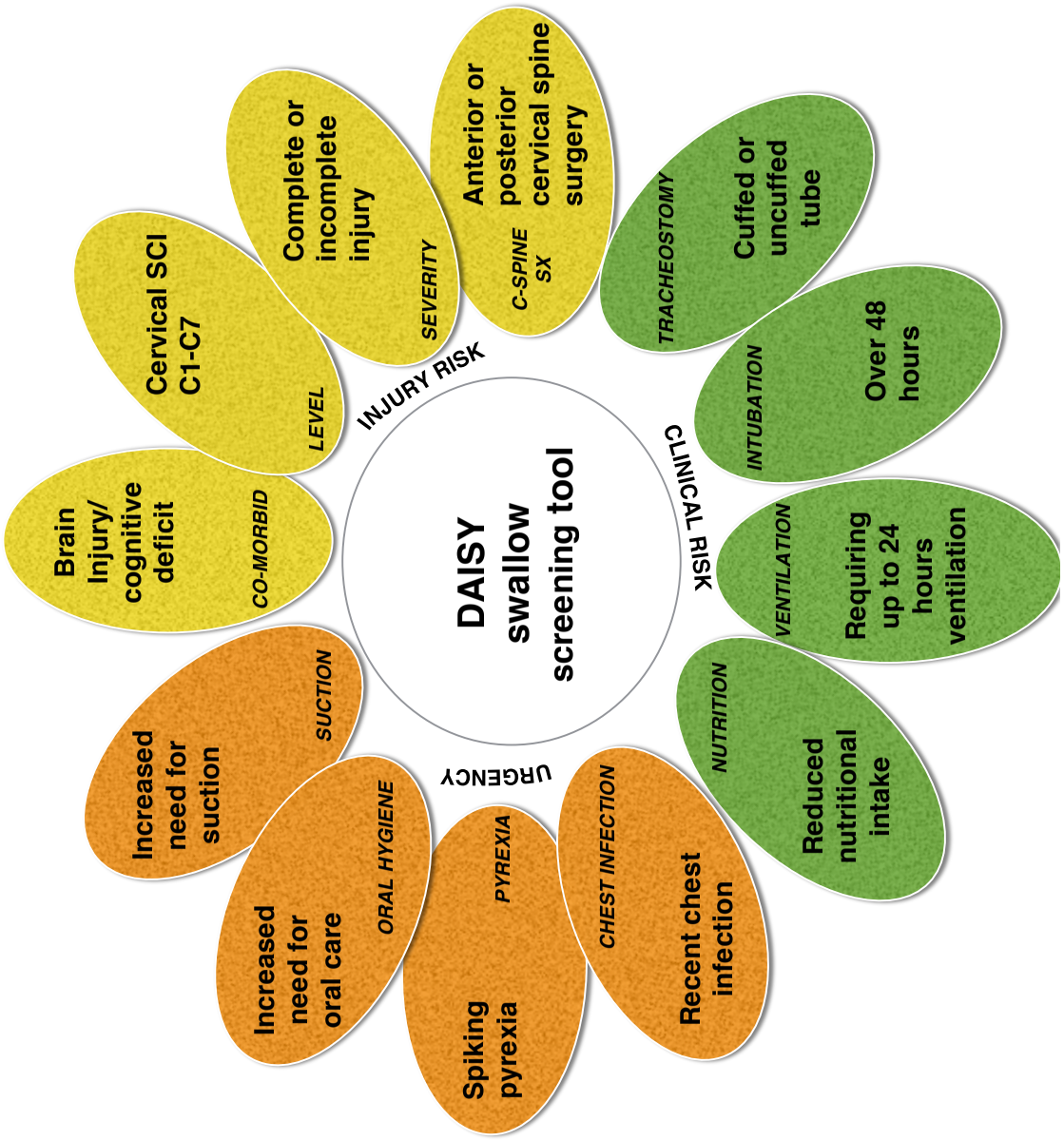
The responses from round 2 have been reviewed and discussed at length with the steering group and supervisory team, alongside a review of the statistical changes between round 1 and round 2 in order to decide whether another round would be required to further clarify the statements without consensus. It is acknowledged that differences are often due to individual practices, so a further round is unlikely to refine responses. The results together with comments provide a great deal of data revealing the challenges in meeting the needs of these patients. This will be written up as practice guidelines for open access to all clinicians.

Components for a swallow screening tool have been identified and will be developed to be used in a small pilot study to assess validity and usability. This will be published with further plans for a multi-centre feasibility study.

Thank you for your support in this study and contributing to the small body of knowledge in this area.

Appendix 25 Delphi round two results by profession

DELPHI R2 Statement no.	Doctor n=5		NURSE n=3		PT n=8		SLT n=8		Dietitian n=2	
	Average	Range	Average	Range	Average	Range	Average	Range	Average	Range
1	3.60	3	4	2	4.25	2	3.63	3	3	2
2	3.80	2	4.33	1	4	2	3.63	3	4.5	1
3	4.20	2	4.67	1	4.25	2	3.88	3	4.50	1
4	3.40	2	2.33	1	3.38	2	3.63	3	3	2
5	3.20	2	4	0	3.25	3	3.75	1	4	0
6	3	3	3.67	4	4.25	2	3.75	3	4	0
7	3.60	2	4.67	1	3.75	3	3.75	2	4	0
8	3	2	3.67	3	3.75	2	3.25	2	4	0
9	3.60	2	3.67	3	4	3	3.38	4	3.50	1
10	3.20	2	3	2	3.75	2	3.29	2	3.50	1
11	4.20	1	3.33	2	4.25	2	4.29	1	4.50	1
12	4	3	4	3	4.13	3	4.13	2	5	0
13	3.20	2	3.67	3	2.63	3	2.25	4	3.50	3
14	3.20	2	2.33	1	3.13	3	3.38	1	1	0
15	2.50	3	3.33	2	4.13	2	3.75	2	1.50	1
16	3.20	3	4	2	4.25	2	3.88	2	3	0
17	1.80	1	2.33	1	2	3	2.63	3	1	0
18	4	3	4.67	1	4.75	1	4.38	2	4.50	1
19	4.40	1	4	3	4	3	4	2	4	0
20	3.60	1	4	0	3.75	2	3.13	3	4	2
21	4	0	4.33	1	4.25	1	4.14	1	4	0
22	3	2	3.33	2	3.38	3	3.63	1	3.50	1
23	4.20	1	4	0	4.25	1	4.25	1	4	0
24	3.60	3	4.33	1	3.75	3	4	2	4	0
25	3.80	1	4.33	1	4.25	1	3.13	2	4.50	1
Average range		1.96		1.64		2.24		2.2		0.72


DAISY swallow screening tool
INJURY RISK
CLINICAL RISK
URGENCY
Anterior or posterior cervical spine surgery
C-SPINE SX
Complete or incomplete injury
SEVERITY
Cervical SCI C1-C7
LEVEL
Brain Injury/ cognitive deficit
CO-MORBID
Cuffed or uncuffed tube
TRACHEOSTOMY
Over 48 hours
INTUBATION
Requiring up to 24 hours ventilation
VENTILATION
Reduced nutritional intake
NUTRITION
Recent chest infection
CHEST INFECTION
Spiking pyrexia
PYREXIA
Increased need for oral care
ORAL HYGIENE
Increased need for suction
SUCTION

Appendix 27 Feasibility study - phase one decision form

Unit ID:

THE DAISY PROJECT
Pilot study
PHASE ONE

To be used with all acute spinal cord injury patients with injury to <u>cervical</u> and <u>thoracic</u> levels

Please document your decision about their change to oral intake. Use one form per decision.

Profession making decision: Date of decision:	Doctor (specialism) ☐ Nurse ☐ PT ☐ SLT ☐ Dietitian ☐ Team (detail team members) ☐ Other (please give details) ☐	Additional comments:
Date of spinal cord injury: Details of level and severity type: Current state of oral intake:	NBM/Tube fed/oral diet	
Decision regarding oral intake: Reason:	NBM ☐ Commence oral intake ☐ Refer to SLT for swallow ax ☐ Other (please give details) ☐	
Any comments about the pilot study:		

When complete, please return this form to the site PI (DETAILS) or post in the DAISY box.

Appendix 28 Feasibility study - phase two decision form

Unit ID:

To be used with all acute spinal cord injury patients with injury to <u>cervical</u> and <u>thoracic</u> levels

Please document your decision about oral intake based on The DAISY swallow screening tool

Use one form per decision.

Profession making decision: Date of decision:	Doctor (specialism) ☐ Nurse ☐ PT ☐ SLT ☐ Dietitian ☐ Team (detail team members) ☐ Other (please give details) ☐	Additional comments:
Date of spinal cord injury: Details of level and severity type: Current state of oral intake:	NBM/Tube fed/oral diet	
Decision regarding oral intake: Reason (please circle areas of concern on tool):	NBM ☐ Commence oral intake ☐ Refer to SLT for swallow ax ☐ Other (please give details) ☐	

TOOL FEEDBACK: **Scale: 1-5**	**1=disagree strongly, 2=disagree 3=neutral 4=agree, 5=agree strongly**	**Comments:**
The tool was easy to understand	**1 2 3 4 5**	
The tool was easy to use	**1 2 3 4 5**	
The tool can be used by any member of the ICU team	**1 2 3 4 5**	
The tool would be beneficial for use with SCI patients	**1 2 3 4 5**	
Any other comments about the tool or use:		

My name is Jackie McRae and I am the Chief Investigator of the DAISY project. This is an NIHR study looking at improving the way we identify dysphagia in acute spinal cord injury patients.

If you are watching this video, then you would like to find out about the DAISY swallow screening tool.

The tool has been developed as a result of expert consensus, but feedback on its value is very welcome.

The tool is divided into 3 sections, called Injury Risk, clinical risk and urgency.

The tool does not need you to do anything to the patient or any scoring, just to tick off the clinical issues that are present. You will need to find out about some clinical aspects. This may be helpful to do as a team.

Starting with Injury Risk –
Does the patient have a brain injury or any cognitive deficit?

Is their injury at the cervical level of C1 to C7?
Is the injury complete or incomplete – this relates to the diagnosis according to the American Spinal Injury Association definition of preserved sacral function.

Has the patient had anterior or posterior cervical spinal surgery following this injury?

Next is the section called clinical risk:
Does the patient have a tracheostomy, whether cuffed or uncuffed?

Has the patient required intubation for 48 hours or more?

Does the patient require ventilation of any amount?

Is the patient's nutritional intake reduced?

If there are positive signs of risk in each of these sections, a referral to SLT should be considered for further diagnostic testing.

The next section is entitled urgency include the presence of recent chest infection, spiking pyrexia, an increased need for oral care and an increased need for suction. These indicate the development of symptoms and a change of clinical management is suggested in addition to referral.

I hope the DAISY swallow screening tool will help staff to better identify the risks of dysphagia and enable earlier intervention.

Please send me your comments through the website at www.daisyproject.info